

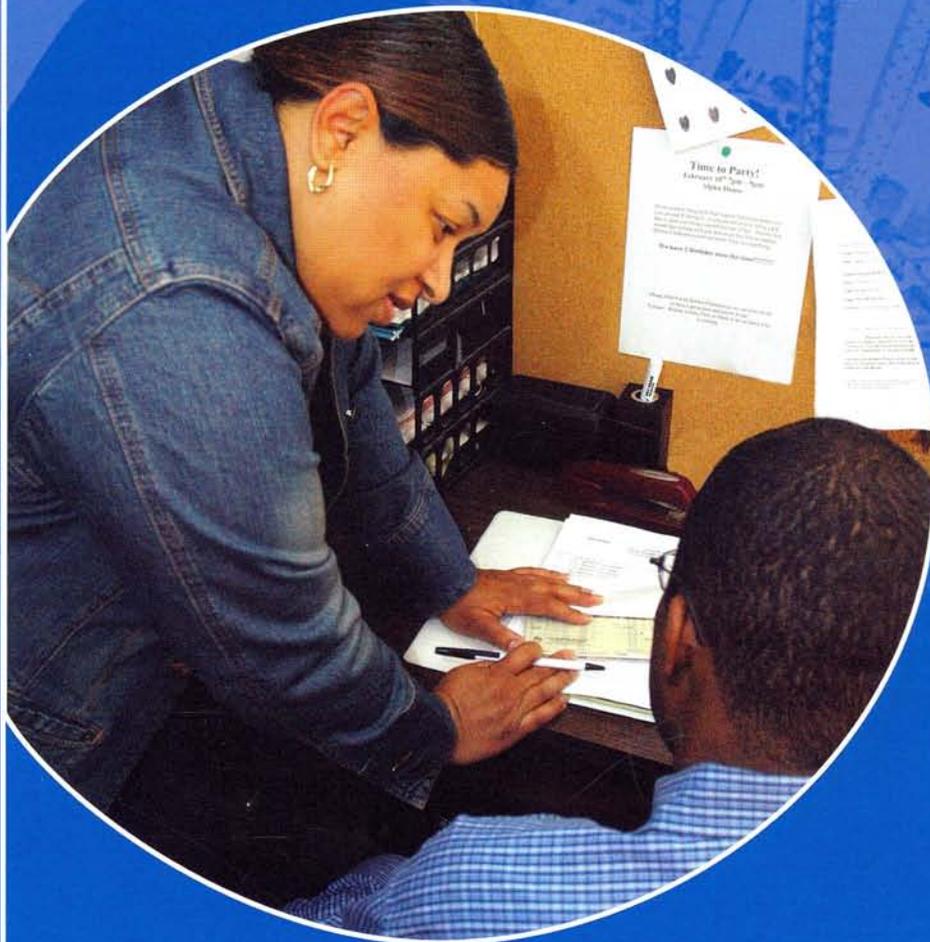
**BUILDING BRIDGES**

**OF SUPPORT ONE**

**PERSON AT A TIME**

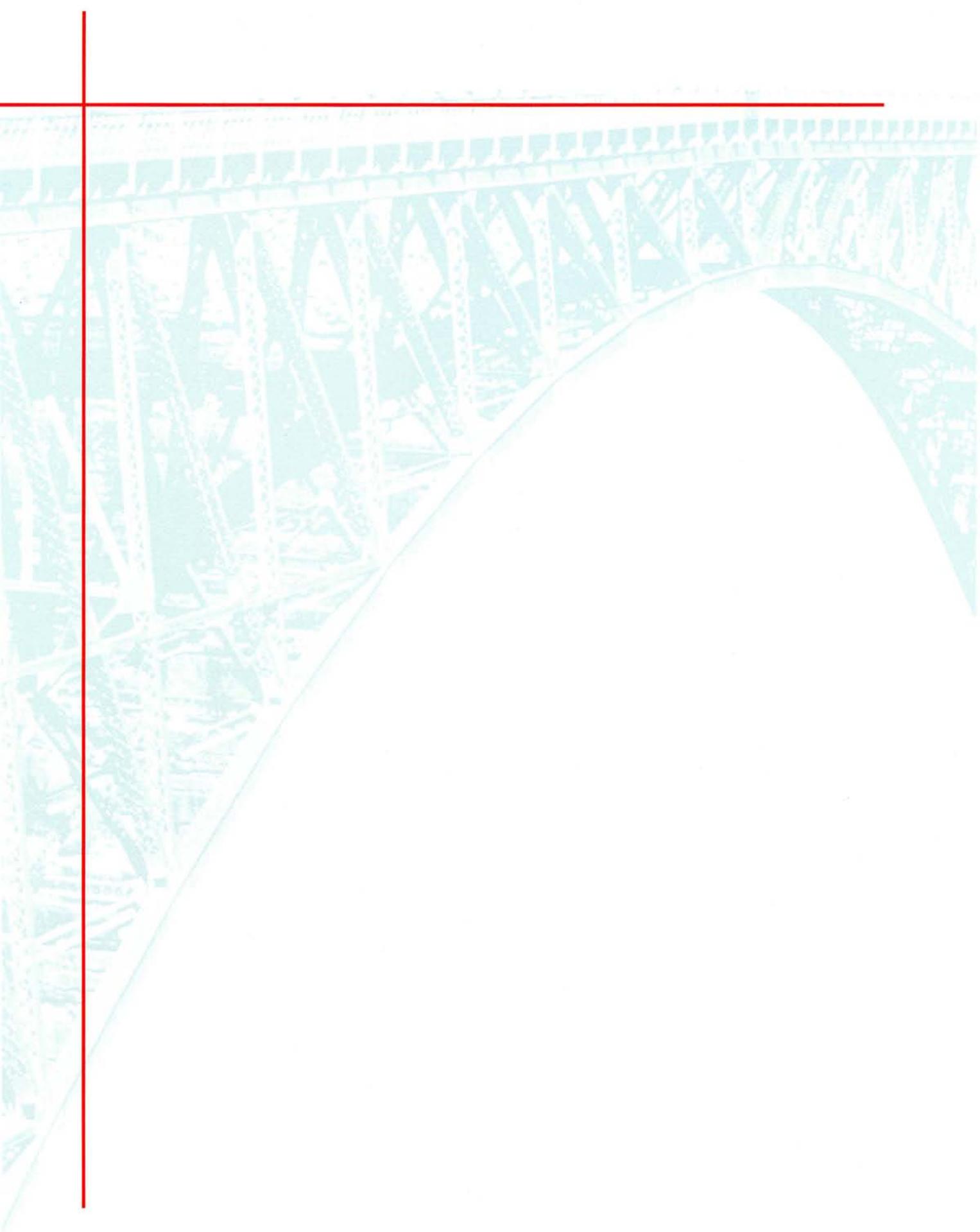


OKLAHOMA DEPARTMENT OF HUMAN SERVICES



**A HANDBOOK FOR GUARDIANS  
OF ADULTS WITH DEVELOPMENTAL DISABILITIES**

Developmental Disabilities  
Services Division



# CHAPTER OUTLINE:

## CHAPTER 1

What is guardianship?  
Types of guardianship  
Misconceptions about guardianship  
Decision making  
Giving consent

## CHAPTER 2

DDSD Guardianship Voucher Program  
Who is Eligible?  
Application Process  
Selecting an attorney

## CHAPTER 3

Guardianship Process  
The capacity assessment  
Finding an appropriate guardian  
Voucher application  
Legal process

## CHAPTER 4

Responsibilities of a Guardian  
The initial plan for the care and treatment  
of the ward  
The annual report  
Advocacy  
Documentation  
Maintaining copies of legal documents

## CHAPTER 5

Liabilities of a Guardian  
Seeking the advice of an attorney

## CHAPTER 6

Limitations of a Guardian  
Reasons for removal of a guardian

## CHAPTER 7

Advance Planning  
Making an estate plan  
Wills

Letter of intent  
Personal information summary  
Precautions  
Trusts  
Tax issues  
Selecting an attorney  
Financial planning  
Other helpful tips

## CHAPTER 8

Coping with Changes and Loss  
Dealing with personal loss  
Grieving

## CHAPTER 9

End of Life Issues: Advance directives and  
Do-Not-Resuscitate consents

## CHAPTER 10

Helpful Web sites for guardians

## Appendix:

AAIDD Statements on  
Sexuality and End-of-Life  
Plan for the Care  
and Treatment of a Ward  
Plan for the Management  
of the Property of the Ward  
Report on the Guardianship  
of the Person (Annual Report)  
Report on the Guardianship  
of the Property (Annual Report)  
Notice of Hearing -  
Annual Report of Guardianship  
Order Approving Annual Report  
Certificate of Mailing  
Information Sheet  
Contact Sheet



## CHAPTER 1

The Oklahoma Department of Human Services Developmental Disabilities Services Division (DDSD) offers guardianship assistance to adults receiving services. Not all adults with developmental disabilities need guardians. That is why DDSD staff takes great care and caution in assessing the need for a guardian and in recommending an appropriate family member or volunteer to serve in that role.

The need for a guardian is based on whether or not a person is capable of giving informed consent. A person is considered incapacitated when he has a mental impairment that affects his ability to receive and evaluate information and make choices. Only a judge can determine whether or not a person is incapacitated through a guardianship hearing.

This handbook was developed specifically for family members and volunteers who have agreed to be guardians of people with developmental disabilities who receive services from DDSD. This book provides information about the role and responsibilities of a guardian, the DDSD voucher program, the legal process, paperwork and documentation responsibilities, limitations and liabilities and other helpful resources.

*The photos you will see in this handbook are of actual DDSD guardians and volunteer advocates with the people for whom they have been appointed to represent. The scenario situations, however, are fictional and are in no way related to the people in the photographs. The scenarios have been written to give examples of some situations guardians may actually encounter.*

## WHAT IS GUARDIANSHIP?

Guardianship is a legal relationship that is established by a judge through a legal process. It can be general allowing the guardian to make certain major decisions for that person, or it may be limited giving decision-making authority to the guardian in only a few areas of a person's life. It may be ordered for only a limited time or even for a single decision.

Guardianship need not be life long, nor is it an all-or-nothing deal. The guardianship relationship can be designed to fit each person's needs and still allow the person to make as many life decisions as possible. The person for whom a guardian has been appointed is called a ward.

## TYPES OF GUARDIANSHIP

When creating the guardianship order, the judge has flexibility. The judge may make specific rules for each guardian in order to preserve as much as possible the person's independence.

**Under the Oklahoma Guardianship Act, there are three types of guardianship:**

1. **General:** A general guardian is a guardian of the person or of all the person's property.

**Guardian of the Person:** This type of guardian has the legal authority to make personal decisions for the ward such as living arrangements, employment, education and what kinds of medical procedures the person should have, but only to the extent that the person cannot make their own decisions.

**Guardian of the Property:** This kind of guardianship gives the guardian the legal authority to manage money or other property of the person, including the person's wages.

2. **Limited:** A limited guardian can make certain decisions for the ward, or about the property of the ward within this state, or both. Limited guardianship is often used for persons who need someone to make medical decisions for them.
3. **Special:** A special guardian is appointed for an emergency purpose and for a set period of time. Generally this period of time is approximately 30 days but may be extended if necessary.

**Scenario**

*John is an individual with a disability. He has always made his own decisions in the past with some support from his team. During his last dental exam his dentist found a tooth that was decayed and it had reached the point of needing to be*

*extracted. To do this, the dentist would have to use anesthesia. The dentist did not feel comfortable accepting John's consent, as it was apparent he did not understand the risks involved with being anesthetized.*

*John's team met and discussed the situation and agreed this was something serious and needed to be addressed immediately. The team recommended that John have a special guardian appointed only to give consent for the procedure.*

The specific responsibilities and limitations of the guardian's role are outlined in the Oklahoma Guardianship Act and may be further detailed in the court's order for each individual.

**The basic role of the guardian is to:**

- Follow the orders of the court;
- Assure that the ward's rights are being protected;
- Assure the essential needs of health and safety are being met;
- Assure that the ward has a place to live which is least restrictive and most normal for his or her health and safety; and,
- Provide required consents or approval as outlined and authorized by the court.

### **Scenario**

*Sally is a 39-year-old with severe physical and cognitive disabilities. She lives in her own home with round-the-clock staff support. She also has significant health issues. Sally's guardian is her mother, Nelda. Over time, problems with the residential provider agency began to increase, including frequent medication errors, not repositioning Sally as needed and improperly prepared food. After reporting these problems to the appropriate agencies, and several attempts by the team to get them resolved, Nelda decided that a change of agencies was needed. The case manager set up appointments with three different agencies for Nelda to interview. She came prepared with a list of questions that she wanted to ask each of the providers. After the interviews, Nelda and the case manager discussed the pros and cons of each agency. Nelda chose the agency she believed would provide the best care for Sally. After several months with the new agency, Nelda continued to be very pleased with the care that Sally was receiving.*



## MISCONCEPTIONS ABOUT GUARDIANSHIP

There are many mistaken beliefs about the role of the guardian. These are a few examples of what a guardian is **not**:

- **A guardian is not a service provider.**  
A guardian has a role in identifying what services a person may need, advocating for and monitoring those services, but it is not the guardian's role to personally provide care or services. Parents who are appointed guardians to their adult children may also provide services to their child, but being the guardian does not make this an obligation.
- **A guardian is not a parent.**  
Being appointed a guardian does not create a parent-child relationship for non-parental guardians, nor does it continue the more encompassing role parents have with their minor children.
- **A guardian is not a controller.**  
Guardianship should not be used as a control mechanism over the person. That is not the intent of the law. A guardian may be given responsibility over specific areas of a person's life, such as medical or financial decisions, but that does not mean the guardian can control every aspect of the person's life.

### **Scenario**

*Jane and Ralph really like each other. It has been reported that they are finding private places to meet. Jane's team met to discuss the situation and did not find any health or safety risks involved in this relationship. Jane's guardian still does not want her to see Ralph anymore. Some of the other members of the team want to look at ways to support Jane in a loving, safe relationship with Ralph. They have suggested she be evaluated and receive training in the area of male and female relationships. Jane's guardian is insisting they be kept apart*

*and is threatening to remove Jane from her home of 20 years. The case manager, speaking to the guardian in private, reminds her that the law does not give her the authority to determine who Jane's friends are, unless there is evidence that the friends are causing Jane harm. The team arranges for some counseling with Jane and her guardian to promote better communication and understanding between them.*

*A copy of the AAIDD Sexuality Statement is included in the Appendix of this handbook.*

## DECISION MAKING

Decision-making is the primary role of a guardian. A guardian should understand the ward well enough to help her make important decisions and to give consent and approval for services. This means developing a close relationship with the ward to know her capabilities, finances, physical and mental health, and other needs.

### **Scenario**

*Mary is a 47-year-old with Down syndrome. She has recently regressed in her abilities and it appears she is experiencing the early stages of dementia, which is common among individuals her age with Down syndrome. The team feels that Mary will need the support of a guardian to help her make decisions, and eventually make decisions for her as her condition worsens.*

The guardianship philosophy of DDSD is for the person to be as involved as possible and the guardian to honor the individual's choices in making decisions on their behalf. Guardians have an obligation to make a diligent effort to find out what the ward's past and current preferences are regarding all decisions that the guardian is authorized to make.

The extent of the ward's disability may determine her ability to be involved in making decisions. Clear statements from the ward regarding, for example, medical care are the most definite ways to know a person's wishes, but those are not always available. If the ward is not able to communicate her wishes, the guardian may need to interview friends, family members, or care providers to learn as much as possible about the lifestyle, values, likes and dislikes of the ward.



Guardians may also consult with the ward's case manager and the team in making important decisions. DDSD case managers have the duty of ensuring the rights of the individual are being protected while needs for health and safety are being met. To assure this, they must provide appropriate support to the guardian and maintain and encourage open communication among the ward's team members.

### **Scenario**

*Roberta is the guardian for her 35-year-old son, Matthew. Matthew lives in a state facility where he receives 24-hour care and supervision to ensure that his medical needs are met. He has frequent seizures and severe osteoporosis. He is unable to walk or sit up and is non-verbal. Matthew is sensitive to changes in air temperature, which limits the days he is able to leave his residence. Roberta attends Matthew's team meetings on a regular basis, during which she works with team members to make decisions about Matthew's care. Roberta visits her son at least once a week, reading to him, looking at photographs, and talking to him about his family. Matthew loves these visits, smiling and grasping Roberta's hand the entire time. Roberta looks forward to these visits and finds joy in the time she spends with her son. She also uses these visits as opportunities*

*to get to know the staff that work with her son and to make sure that they are aware of his desires and preferences.*

## GIVING CONSENT

One of the major acts of decision making is giving consent on behalf of the individual in the areas of his life that are specified by the court in the guardianship order.

Consent means giving permission on behalf of the individual. This does not necessarily mean signing a piece of paper, although consent forms are often involved for medical purposes or in authorizing certain actions. Consent may involve a discussion so that the guardian and the ward, whenever possible, understand for what purpose the permission is being granted. A discussion may also need to take place with the ward's team depending on the issue.

Consent involves making informed decisions. A guardian should never give permission or authorize any action that he does not fully understand. This may require the guardian to ask questions and gather information so that he is comfortable in giving consent. For example, some treatments or procedures are intrusive which means they could be uncomfortable or even painful, or may have side effects that would interfere with the ward's life. All of these aspects must be carefully considered as well as the ward's preferences before making a decision.

### **Scenario**

*Scott has a severe seizure disorder. The doctor is recommending that he have a vagal nerve stimulator implanted that would control his seizures, however, it would be an elective and intrusive procedure. His volunteer guardian, Jake, was asked to consider consenting to the procedure. Since this is an elective medical matter and not an immediate life or death situation, Jake consulted with Scott's DDS team on the issue. After the team meeting, Jake had the information he needed to make an informed decision based on what Scott would probably want if he were able to tell him.*



DDSD has policies to ensure the rights of people being served are not violated and that the best possible health care is maintained. DDSD requires that the ward's team review and approve the following issues:

- Use of psychotropic medication
- Monitoring for medication side effects
- Health services
- Intrusive procedures
- Protective intervention programs

### **Scenario**

*Candace is an incapacitated adult with developmental disabilities. She was in desperate need of a medical procedure after a fluid build-up in her lungs. Doctors would not perform the procedure without a signed consent. Being unable to make informed decisions for herself, Candace's DDSD team, staff, and doctors contacted Candace's volunteer guardian, Linda. Not wanting her friend to be deprived of medical care, Linda rushed to the hospital to sign consent forms in order for the doctors to proceed with the treatment. Candace's mind was put at ease when she saw Linda was there to advocate for her. Linda also ensured that Candace's health and safety were not compromised. After the successful treatment, Candace, Linda, and the DDSD team were able to arrange for her release from the hospital into the comfort of her own home.*

## CHAPTER 2

# THE DDSD GUARDIANSHIP VOUCHER PROGRAM

DDSD can provide help in paying for legal fees associated with guardianship services through a voucher program. A voucher is simply a certificate from DDSD that may be redeemed by an attorney to reimburse him for legal fees. This assistance is available to persons receiving DDSD Home and Community-Based Waiver services and residents of the Northern Oklahoma Resource Center in Enid, the Robert M. Greer Center in Enid, and the Southern Oklahoma Resource Center in Pauls Valley.

## WHO IS ELIGIBLE?

To be eligible for this voucher, the potential guardian must be a relative of the person or be a certified volunteer through the volunteer guardianship agency. The potential guardian must also be recommended and approved by the DDSD capacity assessment team, formerly known as the guardianship assessment team.

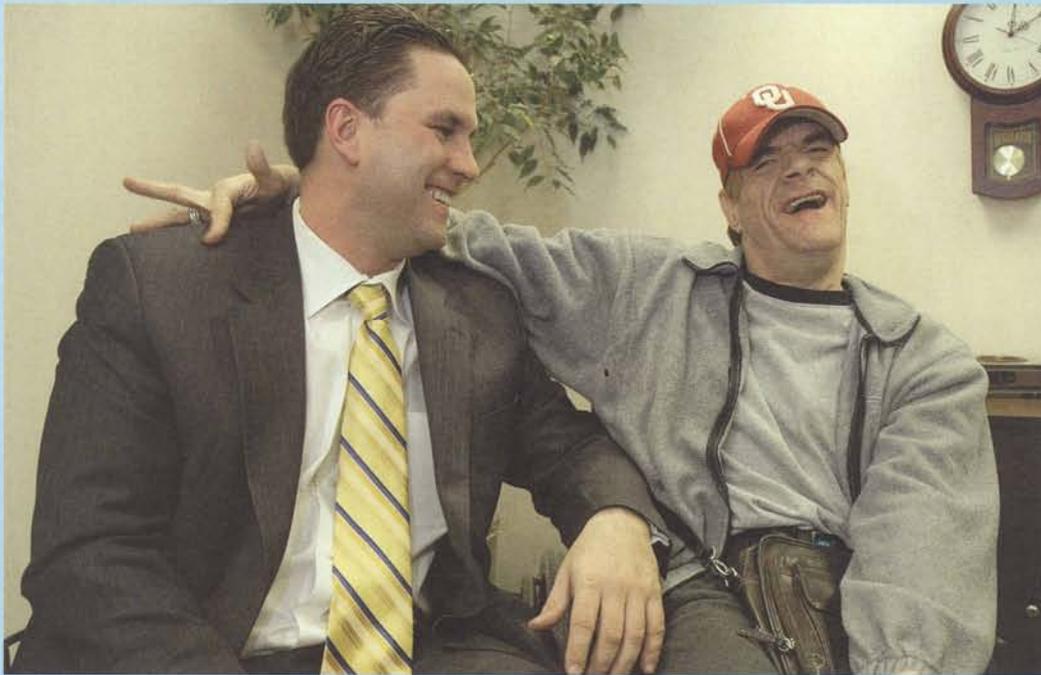
Immediate family members must meet certain financial eligibility requirements to qualify for the voucher. An immediate family member refers to a spouse, mother or father. To be eligible for the voucher, the annual (yearly) adjusted gross income of the immediate family member must be \$60,000 or less. Other relatives and volunteer guardians do not have to meet these financial requirements.

## APPLICATION PROCESS

Information on applying for the voucher can be obtained through the individual's DDSD case manager. If the application is approved, a dated voucher is sent to the potential guardian along with a list of attorneys who have accepted the voucher for their services in the past.

## SELECTING AN ATTORNEY

Guardians may use an attorney of their choice, provided they have a discussion with the attorney and he agrees to perform the services for the amount of the voucher. If the attorney charges more for the guardianship proceedings than the voucher will cover, the guardian will be responsible for the additional costs. Upon completion of the guardianship proceedings, the attorney who provides the service submits the voucher to DDSD for payment. The DDSD voucher is currently worth \$700, but this amount is subject to change. When the voucher is issued, it will state the amount that it is worth. Check with the DDSD Guardianship programs manager if in doubt.



## CHAPTER 3

# THE GUARDIANSHIP PROCESS

The process of becoming a legal guardian has several steps, some of which are taken before the guardian is involved and some are taken before the actual guardianship hearing.



The following is an overview of the steps involved in the DDSD guardianship assessment process:

- **The Capacity Assessment:** A capacity assessment, formerly known as the guardianship assessment, is completed by the individual's team.
- **Finding an Appropriate Guardian:** If a guardian is needed, a recommendation is made for the type of guardianship needed and a person to fill this role – either a family member or friend, or the need for a volunteer is indicated.
- **Voucher Application:** If a family member is recommended, they will receive a voucher application.  
*If financial assistance is needed, the family member completes the application and sends it to the DDSD State Office Guardianship programs manager. (\*skip to bullet #8)*
- If a volunteer is needed, the guardianship coordinator makes a referral to the volunteer guardianship agency to begin the search. The volunteer guardianship agency is responsible for recruiting, training and supporting volunteer guardians for persons receiving DDSD services.
- Once the volunteer guardianship agency finds a suitable volunteer and the person's team approves the match, the volunteer guardianship agency trains and certifies the volunteer.

- The volunteer guardianship agency provides the voucher application to the volunteer.
- The volunteer completes the voucher application and sends it to the DDS State Office Guardianship programs manager.
- \*When the family member or volunteer meets eligibility for the voucher, the DDS Guardianship programs manager sends the voucher, an attorney selection guide, the attorney list, OKDHS and DDS mission and vision statements, and cover letter explaining the next steps.

**The voucher will specify:**

- Type of guardianship recommended  
*(if limited, specifies the limitations)*
  - Names of persons nominated to serve
  - Instructions to contact guardianship coordinator for approval to file a petition for a different level of guardianship or different guardian
  - Voucher amount
  - Expiration date (one year from date of issue)
  - Section for attorney to complete and instructions for attorney to redeem voucher
- 
- The individual's case manager provides potential guardian with capacity assessment and supporting documents.
  - Potential guardian chooses an attorney and gives him or her the documentation, the voucher, and the DDS case manager's name, address, and phone number so he or she can be contacted to testify.



Once an attorney is selected, the following legal process begins:

- The attorney for the prospective guardian prepares a petition for appointment of a guardian. The attorney meets with the prospective guardian who reviews and verifies the information. The petition is filed with the district court.
- A hearing is scheduled. The attorney sends copies of the Notice of Hearing to all those who are entitled by law to be advised that a guardianship hearing is scheduled.
- At the hearing, testimony is presented about the reasons why the individual requires the appointment of a guardian, the level of guardianship required and the qualifications of the proposed guardian.
- If there is an objection to the need for the guardianship or the person who seeks to serve as guardian, the judge will likely appoint an attorney to represent the person and will reset the hearing to give all parties an opportunity to prepare the case for trial.
- Otherwise, if there is no objection, which occurs in the majority of cases, the judge will issue a dispositional order appointing a guardian.



- A guardian has ten days from the date of appointment to file a plan for the care and treatment of the ward and a plan for management of the property of the ward. Often the plans are presented and approved at the hearing. The guardian may request the assistance of the attorney to file this plan.
- A copy of the dispositional order or order appointing guardian and the letters of guardianship need to be mailed to the DDS case manager. If a voucher is used, the attorney will forward copies of the pleadings to the State Office Guardianship programs manager, who will forward copies to the case manager. If a voucher is not used, the guardian needs to provide the copies.
- The dispositional order will include a date for filing of the annual reports, which is usually the anniversary date one year from the appointment of the guardian.
- On that date, the guardian submits the annual report on the person and/or the property of the ward to the court. Copies must be given to the ward and any other individuals who were required to receive notice of the original guardianship hearing. Copies should also be given to the DDS case manager and if appropriate, to the volunteer guardianship agency.
- The judge will review the reports and approve them automatically, unless an objection to the report is filed within 15 days of the filing of the annual report.

- If an objection is filed to the annual reports the judge will set a hearing and hear testimony at the hearing as to the cause for the objection.
- Once the report is approved, the judge will set a new date for the following year when the next annual reports are due.

## CHAPTER 4

### RESPONSIBILITIES OF A GUARDIAN

Being a guardian is no small task. It requires dedication and willingness to do whatever must be done for the ward. Every guardian has certain duties and responsibilities. These duties include filing the Plan for the Care and Treatment of the Ward, filing an annual report, keeping in close contact with the ward, and maintaining certain records and legal documents.

### THE INITIAL PLAN FOR THE CARE AND TREATMENT OF THE WARD

After the court issues the initial Dispositional Order – the guardianship order – the guardian must file the Plan for the Care and Treatment of the Ward as described in Chapter 3.

The plan must detail the necessary services to meet the person's needs. This may be based on the evaluation used by the court to determine the person's capacity and needs.

The plan must state the means for obtaining those services and who is responsible for providing them. A copy of the ward's Individual Plan (IP) or Needs Assessment, as prepared by the DDS case manager, could be included to detail all of these things.

The plan must also include how the person will be involved in decision-making. Remember, one of the roles of the guardian is to encourage growth and development in the person as much as possible. The court has protected the right of the person to be involved in the decisions that the guardian will make.

*A copy of the Plan for the Care and Treatment of a Ward form is included in the Appendix of this handbook.*

# THE ANNUAL REPORT

Each year, the guardian must file an annual report as discussed in Chapter 3. This report is typically due on the anniversary of the guardianship hearing; however, the court may request that the report be filed at some other time. The DDSO guardianship coordinator or the volunteer guardianship agency staff will contact the guardian one month before the annual report is due to the court. These staff will also be available to help prepare the report if needed.

- This report must include the name and address of the ward and of the guardian. It should describe any significant changes in the ward's capacity.
- The services being provided and their relationship to the guardianship plan must be described.
- Any significant actions taken by the guardian or any problems that came up during the year should be included in the report.
- The guardian must state why the guardianship should be continued and why a less restrictive alternative would not meet the needs of the ward. The person's DDSO case manager may be able to provide documentation from team meetings to support the guardian's statements.
- Include copies of medical records, evaluations or other records relevant to the issue of guardianship. If a minor illness occurred during the year that did not affect the person's long-term health or capacity, then there would be no need to include that information in this report.
- Itemized accounting of any funds - money - received on behalf of the ward;
- Any funds spent on the ward's behalf and what was purchased;
- Any compensation requested by the guardian.

If a guardian is also responsible for the ward's property, a separate annual report must also be filed, which includes:

- A complete financial statement of the Financial resources of the ward under the authority or supervision of the guardian;
- An accounting of any receipts or disbursements received, or expenditures made on behalf of the ward;

- Any compensation requested by the guardian;
- Any compensation requested for the attorney of the ward.

An updated guardianship plan must also be attached to the annual report if any changes in the plan are required.

Immediately after filing the annual report with the court, the guardian sends copies of the report and the Notice of Hearing Annual Report of Guardianship to the DDSD guardianship coordinator and case manager and to the people listed in the original notice of hearing who may include any of the following:

- The ward,
- The spouse of the ward (if any),
- The attorney of the ward (if any),
- All adult children of the ward (if any),
- If no spouse or adult children, the parents of the ward, or if there is no parent, all adult siblings of the ward,
- If there are none of the above-listed immediate relatives, then copies of the annual report should be given to at least one and no more than three of the nearest adult relatives of the ward, and
- Any other persons as directed by the court.

Along with a copy of the annual report to the court, there should be a certificate of mailing that lists persons who have been sent copies of the annual report. The purpose of sending copies of the annual report to the persons listed above is so that they may have an opportunity to object to the guardianship if they so choose. If there is an objection by any of those persons, it must be filed within 15 days of the date the annual report is filed.

After the annual report is received, a judge may choose to hold a hearing to review the report. This typically does not happen unless an objection to the report has been filed or if the judge is considering issuing an order rather than accepting the report. If there is no objection and no other hearing is held, the judge will issue an order accepting the report.

*A copy of an annual report form, the Notice of Hearing Annual Report of Guardianship, and certificate of mailing form are in the Appendix of this handbook.*

## ADVOCACY

A guardian is an advocate, which is defined as one who pleads the cause of another. Keeping in close contact with the person is essential to being a good guardian or advocate.

**The law states that any guardian must:**

- Know the ward's capabilities, needs, physical and mental health;
- Maintain contact with the ward. For example, a guardian cannot maintain contact through a third party such as the person's staff or landlord. The guardian must be in direct contact with the ward;
- Assure that the ward's needs are met in the least restrictive environment possible;
- Provide any necessary consents requested by the court; and
- Notify the court if the ward's incapacity has ended.



It is most important that the guardian perform these duties with a sense of advocacy for the ward as an individual. This means:

- Knowing the ward well enough to understand his needs;
- Understanding what services are available to meet those needs, and then making sure the services are delivered appropriately;
- Being involved enough to notice whether the services are meeting his needs or whether any changes have occurred in the ward that require a change in services or the guardianship plan itself;
- Following through on a promise to do something for the ward in those areas the court has made the guardian responsible.

### **Scenario**

*Sharon is a 25-year-old female who is attractive and outgoing. Her grandmother, Lucille, raised her since age six. Lucille is her general guardian. She is very involved in Sharon's life and very concerned about her well-being. Lucille lives about 30 minutes away, but visits at least once a week and calls every day. Sharon has been dating a man off and on for about four years. The two moved in together even though Lucille is opposed to this arrangement. Problems began almost immediately. Marcus, Sharon's live-in boyfriend, expects Sharon to do all the cooking, cleaning and laundry. He gives orders to Sharon's staff and sometimes he plays them against each other. He doesn't want to pay for his share of the groceries because he has other bills of his own. This has caused arguments, which have escalated into an abusive situation. Sharon ignores all advice Lucille tries to give. It is clear to Lucille that Sharon's health and safety are at risk. Lucille meets with the team and the team supports Lucille in exercising her authority as the legal guardian in putting an end to this situation. To be sure that she is acting within the law, Lucille contacts the court in which her guardianship was established and asks the judge for permission to end the relationship.*

## DOCUMENTATION

Documentation is another important part of guardianship. Good record keeping is the key to being a successful and accountable guardian. Even though it may seem time consuming, the records can save a lot of work in the long run. Some of the records can be used in the annual report, the update of the guardianship plan or in an appeal of a decision, if one is requested in the ward's case. Good records can also serve to protect the guardian against any charges of negligence and non-performance of duties.

### **Keep written records of:**

- Visits and phone calls with the ward, including holidays, birthday celebrations, outings, and team meetings.
- Phone calls and correspondence about the ward.
- Contact with case managers, providers, school personnel and others involved in the ward's life.
- Copies of medical records, for example, receipts, doctor visits, physician reports and orders.
- Copy of the ward's Individual Plan or Needs Assessment annually.

*In the appendix of this handbook are forms that can help with record keeping. The Information Sheet helps keep track of names and phone numbers. The Contact Sheet helps record visits, meetings, and phone calls.*

## MAINTAINING COPIES OF LEGAL DOCUMENTS

After the hearing, the guardian will receive a copy of the Dispositional Order and the Letters of Guardianship. These documents should be kept with the initial Plan for the Care and Treatment of the Ward, as well as copies of any subsequently filed annual reports. These documents may need to be referred to should a question arise regarding the guardianship or if proof is needed of the legal guardianship.

It is also important for the guardian to keep copies of all the legal documents relating to the guardianship, as well as contracts that may be signed on behalf of the ward. Depending on the type and limitations of the guardianship, the guardian may be involved in consent, complaints or appeals.

## CHAPTER 5

### LIABILITIES OF A GUARDIAN

According to the Oklahoma Guardianship Act, a guardian is not held liable for decisions made in good faith and within the limits set by the court, as long as the guardian has acted responsibly and without negligence.

For example, when giving consent for medical procedures, consent never authorizes a negligently performed procedure. This means that guardians, acting in good faith, would not be held liable if, for instance, a medical procedure that they gave consent for went wrong.

A guardian can be held liable if he neglects his duties and responsibilities. If a guardian misuses the powers assigned by the court, the guardian may be liable for civil damages as well as criminal penalties.



### **Scenario**

*Liz got into financial trouble by opening a number of credit card accounts and spending unwisely. When her guardian learned of this, he stepped in to assist her with closing the accounts. As her guardian, he was not held liable for her debts and was not required to spend any of his own money in the process. He sent copies of the Letters of Guardianship to the credit card companies, along with a letter directing that the accounts be closed. Neither the guardian nor Liz is responsible for the debt.*

## **SEEKING THE ADVICE OF AN ATTORNEY**

The law does not and cannot specify every situation that might possibly arise. If a guardian has any questions about his liability in any situation, he should seek the advice of an attorney.

## CHAPTER 6

### LIMITATIONS OF A GUARDIAN

There are some limitations, by law, to the things a guardian can decide. Guardians cannot give consent to the following without court approval:

- Withhold or withdraw life supports
- Terminate parental rights
- Abortion
- Psychosurgery
- Organ donation
- Experimental procedures
- Placement in a mental health facility without a court hearing
- Prohibiting marriage or divorce

Guardians only have authority over the areas of a person's life that are specified in the guardianship order.

#### *Scenario*

*James was hit by a car and died soon thereafter in the hospital. Although his guardian believed that James would want to donate his organs, she had no authority to grant permission for this to be done.*

### REASONS FOR REMOVAL OF A GUARDIAN

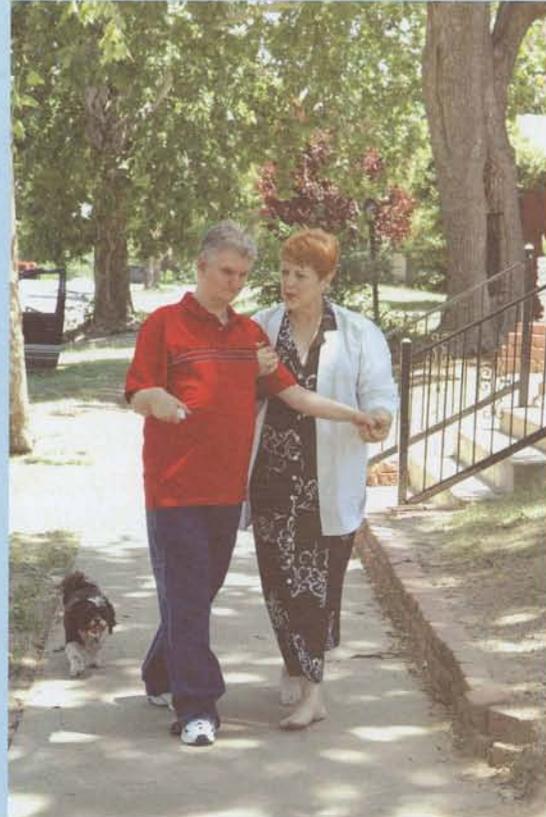
There are certain circumstances under which the court can remove a guardian. The law outlines some of the reasons for removal:

- Abuse of fiduciary (financial) responsibility;
- Continued failure to perform his duties;
- Incapacity to perform his duties;
- Gross immorality; and,
- Having interest adverse to the faithful performance of his duties (conflict of interest).

- The instrument in which the person was nominated as guardian is judicially determined to be invalid. For example, a will names a particular person to be a guardian and then the will is later determined to be invalid, a guardian of the property is insolvent (bankrupt), or when it is no longer proper that the ward should be under guardianship.

### **Scenario**

*Bobby's team met and agreed through the capacity assessment process that Bobby needed a general guardian to assist him in making important decisions. There was no family willing or able to serve so a referral was made to find a volunteer willing to take on this role. The team agreed that Jim, who attends the same church as Bobby, would be an ideal candidate. Jim is the Sunday school teacher for the special needs program in the church. When approached, Jim agreed to do whatever was necessary to fill this role. However, it was learned that his sister is a program coordinator for the*



*residential agency responsible for Bobby's care. Unfortunately, this is a conflict of interest because a critical role of a guardian involves monitoring the provider's performance to ensure the agency is fulfilling its duties and meeting the needs of the service recipient. This could even involve changing providers if deficiencies are not corrected. Jim's objectivity could be called into question because his sister is an employee of the agency. Therefore, the team withdrew their recommendation for Jim to serve as guardian.*

If a ward marries, the court will hold a review hearing to determine what changes, if any, need to be made to the guardianship.

The law also states that a guardian's responsibility ends upon:

- The death of the ward;
- The determination of incapacity of the guardian;
- The guardian's removal or resignation;
- The restoration of the capacity of the ward or the expiration of the term of a special guardian's authority.

The court, after notice and a hearing, may remove a guardian for cause who has failed for 30 days to make an account or a report after he is required to do so.

### **Scenario**

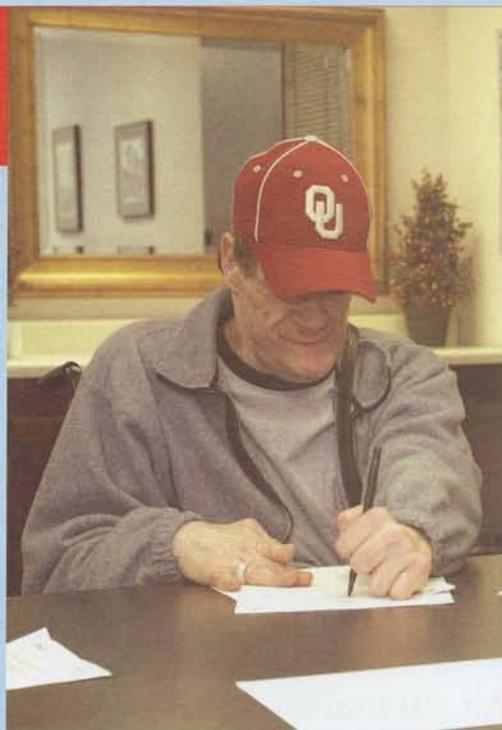
*Beth is a 45-year-old woman with a developmental disability who lived with her sister, Joanne for many years. Joanne was also her guardian. She forced Beth to do all the housework, did not allow her to work outside the home and provided only marginal food and clothing. The court removed Joanne as guardian and appointed Adult Protective Services (APS) to take temporary guardianship.*

*APS made arrangements for Beth to move into a home with two other people, where she has flourished. She works at a sheltered workshop and attends center activities several times a week. She fixes her hair and wears makeup. She is learning to use public transportation. Over time, Beth's relationship with her family has healed, because Joanne is no longer in the stressful role of caregiver. Beth visits Joanne and is included in family celebrations and holidays.*

## CHAPTER 7

### ADVANCE PLANNING

People who are guardians of adults with disabilities should start making preparations for when they are gone. The person's entire family and friends should be involved in planning for the future, and thinking about the roles that each might take in the life of the person with the disability.



Start by making a list of those things that matter – perhaps things that people typically would never think of as needing long-range planning.

### MAKING AN ESTATE PLAN

An estate plan is important for everyone who is preparing for the future of a person with a developmental disability. It should consist of three components:

- a will with letter of intent,
- a special needs trust, and
- personal financial planning.

Everyone understands that estate plans are critical for those who are affluent, but often do not realize that they are equally important for less affluent persons. There are important things to consider even if people believe they have very little to put in a trust, or leave in a will.

## WILLS

Wills can range from very simple to very complex documents. They state a person's wishes for disposing of his assets after death and are important, even if the person thinks he does not have many assets to leave. Wills make it much easier for descendants to handle affairs after a loved one's death.

An attorney should be hired to prepare a will. After death, the individual named in the will to be the personal representative (executor or executrix) must notify beneficiaries and heirs at law of the probate action, determine the value of all assets, notify creditors of the time in which claims against the estate must be filed and keep accurate records of all monetary transactions. When all probate requirements have been met, the estate assets remaining will be distributed to the beneficiaries.

An alternative estate-planning device is a trust. There are several different types of trusts available depending on the needs and desires of the individual. An attorney should be hired to prepare a trust. At death the trustee or successor trustee can handle the affairs of the estate without the need for court intervention. After all debts and taxes are paid, the trustee can transfer the assets to the intended beneficiaries.

Property held in joint tenancy will pass by operation of law to the surviving joint tenants. Often real property owned by married people is held in joint tenancy. Also it is common for bank accounts to be held in joint tenancy by spouses or other family members. Property which has a designated beneficiary such as life insurance policies, retirement accounts, annuities, payable on death bank accounts, and other such items will pass to the named beneficiary by operation of law.

If an individual dies without a will (intestate), their property will be distributed according to the law of intestate succession in the state in which they reside. Each state has a scheme for dividing the property, usually to the family members in the closest degree of kinship to the exclusion of other family members. This may not be the plan the deceased individual would want, so it is best to plan ahead and have a will or a trust.

## LETTER OF INTENT

In addition to having an attorney prepare a will, family members should write a letter of intent. This is a letter to familiarize others with the person with a disability and with the expectations of the family. Regardless of where the person lives – in the family’s home, a group home, or in his own home – the family should communicate to successor caregivers, guardians, and trustees in a letter of intent their knowledge and experience vital to the ward’s best interest. The letter of intent should cover information regarding expectations and preferences regarding the future of the family member, such as:

- Living arrangements
- Education
- Employment or other daily activities
- Supports and services needed
- Important relationships to maintain, including pets
- Medical history and health care needs
- Abilities and needs regarding communication, independence in daily living and personal care, money management and decision-making
- Likes, dislikes and preferences in social and recreational activities, religion, foods
- Effective ways to work with and support the family member
- Financial information such as government benefits, bank accounts, trust, life insurance, and health insurance
- Legal Information such as Social Security number, attorney name and contact information, and locations of legal documents
- Names, addresses and phone numbers of important people or agencies involved with the family member
- Hopes and fears of the guardian for the person
- Anything else that will be important for others to know about the family member

The letter of intent should be copied and given to successor caregivers, guardians, trustees, case managers, agencies serving the person with a disability, and any lawyers involved in setting up the person’s guardianship or special needs trust.

## PERSONAL INFORMATION SUMMARY

An important step in preparing a letter of intent is to create a personal information summary for the person with the disability. This is simply an evolving long-term plan that will provide direction regarding the quality of life desired by the family and their loved one. It is never too early to start and this will ensure not only peace of mind for the family, but also ensure that those who survive will have guidance regarding how to reach and maintain this quality of life.

### *Scenario*

*Karen and Ed were both killed in an automobile accident. Their only child, Sam, is 25 years old with developmental disabilities. Prior to the accident, Karen and Ed supported Sam in finding someone who respected his values and beliefs – someone who was willing to make critical decisions about Sam’s life based on those values. Sam signed a durable power of attorney, naming this close family friend as the agent. Since Karen and Ed’s death, this friend plays an important role in assisting Sam to maintain the quality of life that he and his parents built.*

Discuss this with the person with the disability. When selecting future guardians or caregivers, the family should be sure their choice is also the choice of their loved one with a disability. Remember that this guardian or caregiver is the person that may have significant control over his life and it should be someone who understands his likes and dislikes and can comfortably communicate with him.

Discuss this with the potential future caregiver or guardian. The family should specifically discuss duties and responsibilities with potential caregivers and guardians. This will ensure that these persons understand the wishes and goals of the family and of their loved one with the disability, and that these persons are willing to pursue these same goals or able to communicate with their loved one when changes are necessary and will try to reach mutual consent whenever possible.

## PRECAUTIONS

Sometimes parents or other family members leave money intended for the person with the disability to another family member with instructions for them to spend X amount of this money for the benefit of the family member with the disability. This is not always the wisest decision to make. Even if the person receiving the money uses it as intended, things could happen that would prevent the money being available to the family member with the disability.

### **Some examples are:**

- If the person receiving the funds for the benefit of a disabled person were to require nursing care, the money would be required to pay for nursing home care – legally it would be considered that person's money.
- Creditors could take the money to satisfy claims.
- If the keeper of the money died, the money would then go to his heirs rather than to the person with a disability.

Leaving assets to an agency or organization with expectations that the agency will care for the family member with the disability for the rest of his life may not be safe or reasonable. If the leadership of the organization or financial condition of the agency changes there is no assurance the family member will be protected.

Give careful consideration to how anything left as an inheritance will affect the family member's eligibility for government benefits. For example, there are financial limits which change frequently regarding eligibility for Supplemental Security Income (SSI). Leaving assets in excess of that amount could make the family member ineligible for SSI, and possibly Medicaid as well. Also, Oklahoma law allows the state to take property owned by a person with disabilities to pay for current or past services provided by the state.

## TRUSTS

One way to avoid ineligibility for government benefits due to excessive assets is to establish a supplemental or special needs trust. A properly worded trust would protect against exceeding the limited asset requirements for SSI or other similar governmental programs based on need. The trust funds would not be available directly to the family member with the disability, so the government benefits would continue without interruption. Remember to always check with current laws and regulations before proceeding as Congress can change policies that impact government benefits and personal finances.

A trust is a legal document that provides a way for assets to be handled for someone else, including money or property. A supplemental needs trust is a trust created to supplement government benefits the person with a disability is receiving without jeopardizing the benefits. This trust specifically states that the funds are to be used to supplement, but not supplant or replace government benefits. A statement would be included in the trust regarding who should receive the remaining funds in the trust after the disabled family member dies.

A trust may be created by a parent or any other family member or interested person. This person, called the “grantor” can fund the trust by titling bank accounts, stock, or other assets in the name of the trust. The trustee is the person responsible for managing the trust fund for the benefit of the person with the disability, called the beneficiary. The trustee has complete control over the assets in the trust, but is obligated to use those assets only on behalf of the beneficiary. The grantor may also be the trustee. Co-trustees may, with differing skills and interests in the person with the disability, be a safer choice than one trustee.

Trusts may be revocable or irrevocable. A revocable trust is one that can be changed or terminated at any time during the grantor’s lifetime. The assets in a revocable trust are still considered to belong to the grantor and the grantor can regain possession of them. An irrevocable trust is more permanent and cannot be changed or revoked. The assets in the irrevocable trust cannot be taken back as they are no longer considered the assets of the grantor.

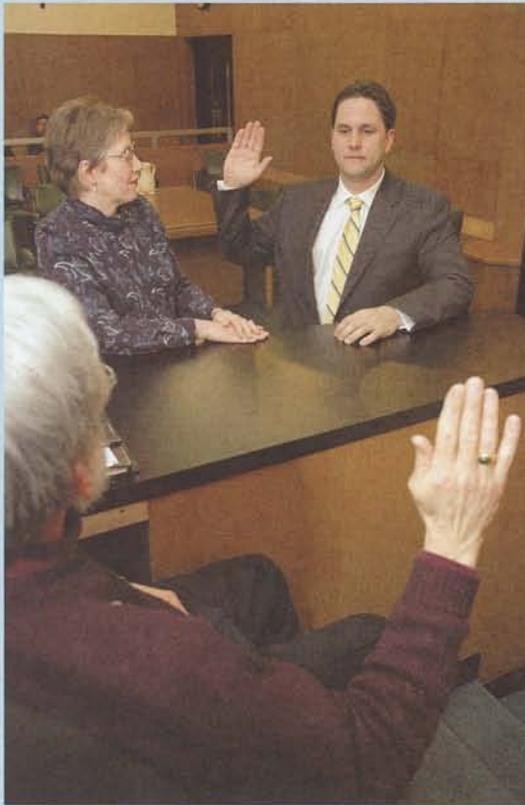
Trusts should always be drawn up by attorneys who are experienced in preparing trusts for persons with disabilities and specifically experienced with Oklahoma trust laws since it includes provisions that no other state includes. Trusts have several advantages – they avoid some aspects of probate, can protect government benefits, and help ensure that the family member’s quality of life can be maintained.

Since the trustee is responsible for administering the trust, it is important for the grantor to carefully select someone to serve as trustee or as successor trustee, who has the ability to administer the trust properly, and whom they believe will handle the funds competently. Sometimes a family member or friend is chosen to be the trustee; sometimes a financial institution is selected. Financial institutions usually manage trusts of larger amounts, do not monitor the personal welfare of the person, and charge fees for services based on the amount of the trust. Such charges can significantly reduce or even consume the assets in the trust. If a friend or family member is named, the trust may address financial compensation for the trustee’s time and service.

## TAX ISSUES

In the planning process, do not overlook tax issues. There are several different kinds of taxes that may be imposed – gift and estate taxes, inheritance taxes, income taxes and capital gains taxes. Be sure to consult an attorney or a tax accountant regarding these issues.





## SELECTING AN ATTORNEY

In selecting an attorney to assist with these legal documents, select one that is familiar with:

- Wills,
- Special Needs Trusts, other trust options and tax implications,
- Public benefits such as SSI, SSA, Medicaid and Medicare,
- Other sources of income, for example, pensions, survivor benefits and annuities,
- Guardianship and other alternatives,
- Health Insurance,
- Life Insurance,
- Capabilities and needs of the family member with a disability, and a general awareness of community service options for people with disabilities.

## FINANCIAL PLANNING

Financial planning usually involves developing ways to achieve financial goals. A financial planner may be an accountant, broker, or insurance agent who can offer comprehensive financial planning services. Select one with the same expectations as when selecting an attorney.

Not everyone will need a financial planner, but regardless, family members should be sure to compile and be familiar with their own individual financial situation. Financial planners will need to review the total financial picture and develop income goals that are the most advantageous to the family.

## OTHER HELPFUL TIPS

Organize important papers so they can be easily found. Be sure to include:

- Birth certificates,
- Marriage certificates,
- Divorce papers,
- Child support orders,
- Naturalization papers,
- Legal agreements,
- Stocks, bonds, CDs, IRAs, other investments,
- Deeds,
- Insurance Policies,
- Income tax returns,
- Financial records,
- Guardianship papers,
- Advance Directives, Living Wills and Health Care Surrogates for both parents and the family member,
- Power of attorney for both parents and the family member, if appropriate,
- Wills,
- Letters of Intent,
- Trust Agreements,
- Names and addresses of people named in the power of attorney, trusts, and wills,
- Burial instructions.

Each estate plan is unique, designed to meet the needs of one special individual. Involve other family members in planning whenever possible. To the extent of his capabilities, include the family member with a disability in the plan for his future.

Important Reminder – Be sure other people who are significant in the family member's life know where the legal documents are kept.

## CHAPTER 8

# COPING WITH CHANGES AND LOSSES

Planning ahead for the family member with a disability means not only preparing for his welfare and quality of life after the death of his parent or primary caregiver, but also preparing him to handle the loss itself. Death is a little discussed subject in American culture and yet at some point in everyone's life, they must deal with the death of someone close to them. The ease with which people survive times of stress or personal loss is dependent upon one's coping skills. How each person deals with stress is the result of what they have learned.

People with cognitive disabilities will be able to deal better with the loss of a loved one if they have been given opportunities to develop and strengthen these coping skills. This learning may come from family experiences, religious teaching, educational training, or simply through association with friends and neighbors. It is important that people with developmental disabilities be given an opportunity to develop successful coping skills that result in good mental health and acceptable behavior.



## DEALING WITH PERSONAL LOSS

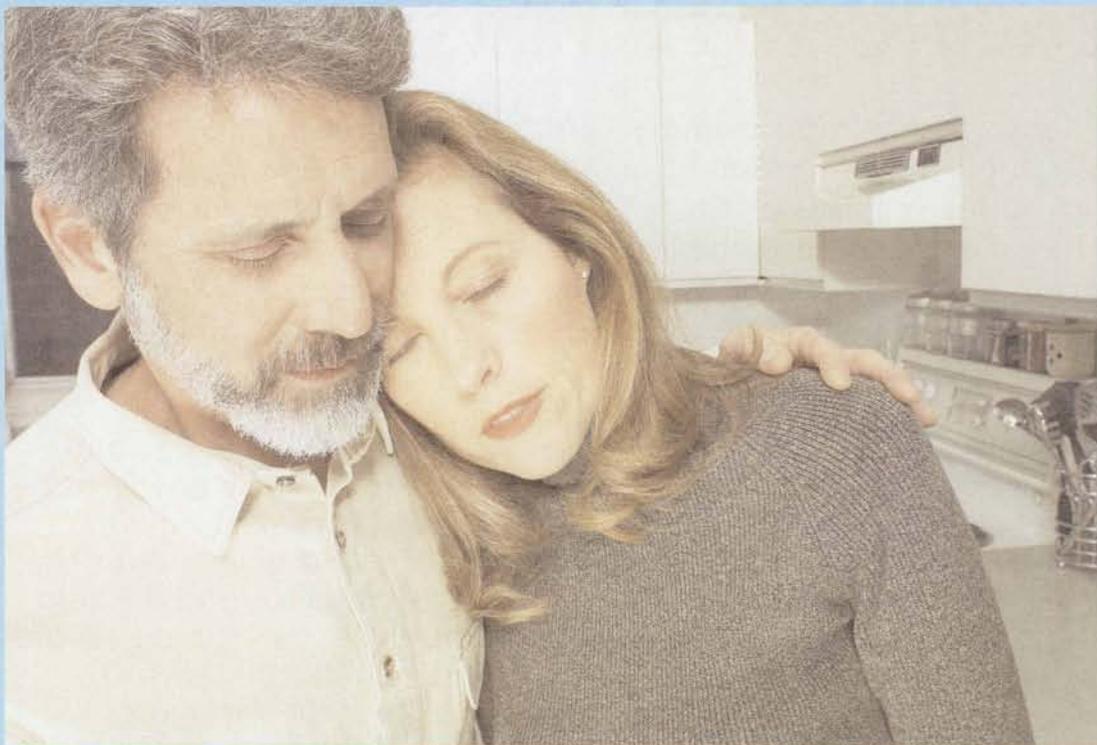
Friends, neighbors, primary caregivers and service providers, although well intentioned, may try to protect the person from facing his feelings at the loss of a family member or friend. They may mistakenly believe that they are saving the person from upsetting emotions that he could not possibly understand. All people experience losses and to some degree, can understand death.

It is important that the person be informed of the loss, and given the opportunity to cope with it. This is more easily done if before the loss there has been discussion regarding what death is, and how one is likely to feel sad and grieve over the loss. If this is not possible, it is still essential to inform, help with understanding, and allow the person to participate to the degree possible in the funeral or other rituals related to the death. Remember that these rituals are to help survivors understand their feelings, express their grief, and improve their ability to cope with future losses.

## GRIEVING

Individuals who have difficulty communicating their feelings may express them through changes in behavior. This may be misinterpreted and discouraged, rather than being used as an opportunity to help the person more appropriately express grief and sadness. By recognizing the reason for the behavior, friends and caregivers may have an opportunity to help the person work through his feelings of loss and grief, thus avoiding long lasting behavioral and emotional problems.

Sometimes a person with developmental disabilities may not react immediately to a severe loss. Therefore, the family or a caregiver may not always recognize that an unexplained sadness, despondency or inappropriate behavior is related to a death or other severe loss such as changes in staff or moving to a new environment.



Remember that grieving takes time. This period can last from a few weeks to years. Be patient and understanding. The best way to help a person through such a loss is to recognize the loss, understand his feelings, and help him express them. With this knowledge and support the pain of grief will gradually diminish. There are things that can help the person with a disability cope with changes and loss.

**In the event of a death:**

- Tell the individual immediately when a family member or friend dies. Be sensitive in selecting who informs him and how it is done. Remember that abstract thoughts may be difficult for him to understand, so be as concrete as possible in describing what death means.
- Encourage the individual to participate in any family rituals, for example, attending the wake, the funeral and interacting with family and visitors.
- Realize that one person's death may remind the individual of previous losses and unresolved grief.
- If possible, call upon an appropriate counselor or spiritual advisor who recognizes the need to grieve and is experienced in relating to persons with disabilities.
- Allow the person to express feelings of grief, regardless of the cause. Remember, grieving takes time – weeks, months, and even years.
- Communicate with the person on a consistent basis about the acceptability of grieving.
- Don't avoid the person, or change the subject when the loss is mentioned.
- Be patient. The individual's progress may be erratic, and include times of confusion, forgetfulness, or denial.
- Communicate in a way and on a level that the person can understand. Recall pleasant times together that they have shared.

If the person with the disability does not live with his family, but is in a community placement or residential facility, discuss with staff and friends what has happened and encourage them to talk with him about his sadness and about the deceased person and their relationship. If the policy of the residential facility has been to avoid discussing death and grieving, encourage them to initiate a learning experience for the group.

## CHAPTER 9

### END-OF-LIFE ISSUES: ADVANCE DIRECTIVES AND DO-NOT-RESUSCITATE FORMS

Family members should plan ahead for their own funerals and discuss these plans with their loved one with a disability. Give him an opportunity to understand why these plans must be made now. Use this as an opportunity to talk about life and death, and what it means within the context of the family's religious or spiritual beliefs.

After discussing the concept of death, family members may wish to learn how their loved one feels about planning for the end of his own life. This would be a good time for the family to discuss end-of-life issues like Advance Directives in Health Care and Do-Not-Resuscitate (DNR) consent forms. Advance Directives can be used to withhold or withdraw life-sustaining treatment, including food and water. By contrast, the DNR consent form is used to withhold only cardiopulmonary resuscitation (CPR). The Advance Directive goes into effect when the attending physician and another physician determine that the individual is no longer able to make decisions regarding medical treatment and determine that the individual is either terminal (death is expected within six months), persistently (long-term) unconscious, or has an end-stage condition or other condition specified by the person. The DNR consent form goes into effect upon signing and should only be signed by an individual who is near death and ready to die. A guardian must obtain a court order to sign a DNR for their ward. Guardians may not sign Advance Directives for their wards.

These wishes should be discussed with family members and forms signed ahead of time where appropriate. These forms should be shared with the person's physician and a copy placed with other important papers and included in the long-term plan or personal information summary of the person with a disability.

## CHAPTER 10

# HELPFUL WEB SITES FOR GUARDIANS

**<http://www.retirementnightmare.com>**

lists the state Guardianship Act, statutes, and such items

**[www.specialneedsalliance.com](http://www.specialneedsalliance.com)**

Special Needs Alliance – forms for letters of intent and other resources

**[www.okdhs.org/aging](http://www.okdhs.org/aging)**

Oklahoma Department of Human Services Aging Services Division – End-of-Life legal forms, Advance Directives and Do-Not-Resuscitate Consent forms, durable powers of attorney

**[www.okdhs.org/ddsd](http://www.okdhs.org/ddsd)**

Oklahoma Department of Human Services Developmental Disabilities Services Division – information about DDSD programs and services, contact information for case management and area offices, provider agency lists, and other such items

**<http://www.oklahomadisabilitylaw.org>**

**<http://www.redlands-partners.org>**

Resources

**[www.ok.gov](http://www.ok.gov)**

lists all state agencies, including those for developmental disabilities

**<http://www.soonersearch.odl.state.ok.us>**

links to Developmental Disabilities Council and other helpful resources

**<http://www.ssa.gov>**  
Social Security Administration

**[www.okrehab.org](http://www.okrehab.org)**  
Oklahoma Department of Rehabilitation Services

**[www.youoklahoma.com](http://www.youoklahoma.com)**  
Oklahoma Developmental Disabilities Council

**[www.okparentnetwork.org](http://www.okparentnetwork.org)**  
Families of children and adults with developmental disabilities

**<http://oasis.ouhsc.edu>**  
OASIS - resources

**<http://www.oil.cwis.net>**  
Oklahomans for Independent Living

**[www.hearclink.org](http://www.hearclink.org)**  
The ARCLink-Oklahoma Web site

**[www.ddadvocacy.net](http://www.ddadvocacy.net)**  
TARC - resources for families as well as volunteers

**[www.albany.edu/aging/lastpassages/index.html](http://www.albany.edu/aging/lastpassages/index.html)**  
Last Passages

## APPENDIX

### STATEMENTS AND FORMS

**AAIDD\* Statement on Sexuality**  
**AAIDD Statement on Caring at the End-of-Life**  
**Plan for the Care and Treatment of a Ward**  
**Plan for the Management of the Property of the Ward**  
**Report on the Guardianship of the Person (Annual Report)**  
**Report on the Guardianship of the Property (Annual Report)**  
**Notice of Hearing Annual Report of Guardianship**  
**Order Approving Annual Report**  
**Certificate of Mailing**  
**Information Sheet**  
**Contact Sheet**

\*AAIDD = American Association on Intellectual and Developmental Disabilities, formerly AAMR.

## AAIDD SEXUALITY STATEMENT

People with mental retardation and related developmental disabilities, like all people, have inherent sexual rights and basic human needs. These rights and needs must be affirmed, defended, and respected.

### ISSUE

For years, people with mental retardation and related developmental disabilities have been thought to be asexual, having no need for loving, fulfilling relationships with others. Individual rights to sexuality, which is essential to human health and well-being, have been denied. This loss has affected them broadly in gender identity, friendships, self-esteem, body image and awareness, emotional growth, and social behavior. Our constituents frequently lack access to appropriate sex education in schools and as adults and to training in parenting and child-rearing. At the same time, people with cognitive limitations often engage in sexual relations as a result of poor options, manipulation, loneliness or physical force rather than as an expression of their sexuality.

Moreover, the general public maintains other out-of-date views of the sexuality of our constituents. Many people have an unfounded fear that parents with mental retardation cannot raise or financially support their children and thus will require more government support, including placement of children in the foster care system.

### POSITION

Every person has the right to exercise choices regarding sexual expression and social relationships. The presence of mental retardation and related developmental disabilities, regardless of severity, does not, in itself, justify loss of rights related to sexuality.

All people have the right within interpersonal relationships to:

- Develop friendships and emotional relationships where they can love and be loved and start and stop the relationships as they choose.
- Dignity and respect.
- Privacy, confidentiality, and freedom of association.

With respect to sexuality, individuals have a right to:

- Sexual expression, reflective of age, social development, cultural and moral values, and social responsibility.
- Information to allow informed decisions, including sex education about such issues as safe sexual practices, sexual orientation, sexual abuse, and sexually transmitted diseases.
- Protection from sexual harassment as well as from physical, sexual, and emotional abuse and sexual relationships with paid staff.
- Have sexual relationships, including marriage, with individuals of their choice.

With respect to sexuality, individuals have a responsibility to:

- Consider the values, rights, and feelings of others.
- Seek input from families, friends, religious leaders, and others on the personal and societal values associated with sexuality.

With respect to the potential for having and raising children, they have the right to:

- Choices related to birth control, including the decision to have and raise children, with supports if necessary; to accept personal responsibility for these decisions; and to have control over their own bodies.
- Have, on an individual basis, access to the proper supports to assist them in raising their children within their own home.
- Choose for themselves whether or not to be sterilized, regardless of the severity of their mental retardation.

# CARING AT THE END OF LIFE

## Reprinted from the American Association on Intellectual and Developmental Disabilities (AAIDD) Position Statement

### I. Purpose and Scope

- A. Clinical experience, public attitudes, medical practice, and legal opinion concerning caring at the end of life vary significantly across the United States. This lack of clarity can jeopardize sound decision-making. Evidence exists to indicate that people with intellectual or developmental disabilities are particularly at risk when caregivers do not have clear, consistent, and ethically sound guidelines. The foundations for such guidelines are discoverable through analyses of existing medical, ethical, legal, and policy deliberations. The purpose of this Position Statement is to identify these foundational principles and to enunciate policies that should guide care at the end of life for persons with intellectual or developmental disabilities.
- B. The end of life is defined here as the last six months of life, which is consistent with the current standard for hospice care. Individuals are not at the end of life when they are living in a stable condition that requires significant life-sustaining treatment (such as a mechanical ventilator or a feeding tube) and wish to continue receiving such treatment. Individuals may be considered to be at the end of life when: (1) they have a condition that is progressive and irreversible, such as late-stage Alzheimer disease or terminal cancer; or (2) they have a condition or functional impairment that is not in itself progressive, improvement or recovery is not expected, and withdrawal of life-sustaining treatment is under consideration. Life may come to an end suddenly and unpredictably (for example from a fatal injury), in which case the policies expressed here will ordinarily not apply.
- C. Discussions about caring at the end of life should begin before the last six months of life. These discussions should include statements about what care the person would like to receive if he or she were in one of the end of life conditions described above. Identification of every possible situation is not feasible, so these discussions should be sufficiently general to cover most situations yet specific enough to provide practical guidance. Legal or other professional assistance will be helpful when developing living wills, health care proxies, durable powers of attorney for health care, and other such statements about personal preferences. These statements should be updated periodically (perhaps every few years), taking into account medical advances, technological improvements, and changing perspectives during one's lifespan.
- D. This Position Statement applies to persons with intellectual or other developmental disabilities who are at the end of life as defined above. "Intellectual disability" is defined here to include all persons with a diagnosis of mental retardation. Such persons may be of any age from childhood to old age. The Principles outlined below define the context in which caring should be provided to all such persons who are at the end of life. The Policies outlined below specify which interventions are permissible at the end of life and which are not.

## II. Principles

- A. AAIDD recognizes four major principles which form the basis for disability policy: (1) Dignity (an ethical principle); (2) Autonomy (a constitutional principle); (3) Life (a constitutional principle); and (4) Equality (a constitutional principle). These principles are explained below and related to end of life care.
- B. **Dignity:** All persons with intellectual and developmental disabilities are valuable and deserve respect consistent with human dignity.
1. All persons are equally valuable (with or without disability). The value of a person's life is not related to the type, degree, or severity of disability. Inherent value must be distinguished from quality of life. Inherent value persists from birth to death, even though the quality of life may change as one approaches the end of life.
  2. The quality of one's life must be assessed from a subjective viewpoint, that is, from the point of view of the person with a disability. Having a disability is not by itself a form of suffering. Non-disabled people who fear becoming disabled must not assume that their feelings are shared by those who are living with a disability.
  3. The mere presence of an intellectual or developmental disability (or likelihood of having an intellectual or developmental disability in the future) does not make the person's life less valuable.
  4. Decisions about care at the end of life must be made respectfully, consistent with the principle of Dignity. Withdrawing or withholding care may be appropriate in some situations but should not itself imply lack of respect for the importance of that person's life. Treatment should not be withdrawn or withheld only because the person has a disability.
- C. **Autonomy:** Caregivers should always try to discover what the person with intellectual or developmental disabilities wants (as much as possible) and honor those wishes.
1. All people express preferences through their speech and/or behavior. Careful observation and interaction over time will clarify what a person with intellectual or developmental disabilities believes is important. Those who are closest to the person (ordinarily the family, also trusted caregivers, nurses, friends, and others) are best able to identify the person's preferences when the person is unable to express them directly.
  2. Individuals with intellectual or developmental disabilities should be encouraged to express their preferences about care at the end of life before situations requiring decision-making occur, if possible. Many children, adolescents and adults with intellectual or developmental disabilities are capable of expressing their preferences about end of life care and efforts should be made to discern their wishes in this regard. These preferences should be documented utilizing any of a variety of ways to do so, including (but not limited to) living wills, personal vision statements, health care proxy instructions, and other indicators of one's wishes.

3. Decision-making capacity may vary in different situations. Health care providers must recognize that individuals with intellectual or developmental disabilities whose legal competence is challenged nonetheless may have the capacity to express preferences about health care. These preferences should ordinarily be respected.
4. The principles of informed consent require that decision-makers have: (1) all of the information needed to make a decision; (2) the ability to assess the information adequately; and (3) freedom from undue influence by others. Caregivers must always seek to determine the uncoerced, authentic voice of the person with an intellectual or developmental disability and provide all of the information the person needs to express his or her preferences. Instructional strategies and training materials should be developed that will assist individuals with intellectual or developmental disabilities to access relevant information, analyze it effectively, and utilize it to assess options and make choices.
5. The process of self-determination helps individuals to apply the principle of autonomy in their lives and to identify their health care preferences clearly and effectively. Self-advocacy recognizes the autonomous, constitutional right of individuals with intellectual or developmental disabilities to have their preferences respected.

**D. Life:** Caregivers should act to promote and protect the life of the person with intellectual or developmental disabilities.

1. The best-interest standard should be the relevant basis for making decisions about treatment to promote and protect life. Normally the person determines what is in his or her best interest, and this takes precedence over all other determinations. When that is not possible, others may do so when they follow accepted legal procedures defined by state and Federal laws and regulations.
2. In some situations, continued life may not be in the person's best interest. Existing law recognizes such situations as those where: (1) life-sustaining treatment is clearly ineffective and would only prolong the process of dying with no prospect of reversing it; (2) the person is in an irreversible coma or permanent vegetative state (when those conditions are identified by qualified expert neurological consultation); or (3) the treatment itself would impose excessive pain and suffering.
3. People for whom religion and spirituality are important (including people with intellectual or developmental disabilities) may believe that forgiveness, reconciliation, peace or eternal life with God is more important than continued life on earth. This judgment about the person's religious or spiritual preferences should be made by the individual or his or her loved ones and should not be determined solely by health care providers.

**E. Equality:** Resources for caring at the end of life must be appropriate, sufficient, and available without discrimination.

1. The current system of health care in the United States often does not provide adequate resources for persons with intellectual or developmental disabilities. Such persons depend on public health care financing (Medicaid and Medicare), which may restrict access to needed treatment.

2. Needed treatment should be available in the most appropriate context, taking into account the person's preferences and health care needs. People should not be required to live in a nursing home in order to get care that could be provided in a more natural setting such as the person's home.
3. Needed treatment includes (but is not limited to) provision of home health care, nursing, medications, nutrition, hydration, and social interaction. Hospice care at the end of life should be available when it is appropriate. Adequate pain relief is essential to alleviate and prevent suffering at the end of life. Spiritual or pastoral care should be provided when it is desired. All needed treatment must be provided. Public and private health insurance should cover these needs.
4. Economic incentives for reducing the cost of health care (such as rationing or managed care) may induce providers to restrict or deny life-sustaining treatment for persons with intellectual or developmental disabilities. Providers should treat all patients equally regardless of the presence or absence of such disabilities and provide whatever resources are needed in the particular context.

### III. Policy

- A. Permissible treatment options at the end of life are the same for persons with intellectual or developmental disabilities as for everyone else. This reflects the Equality Principle.
  1. The wishes of persons who have clearly and competently expressed them should be honored by caregivers and health care providers, consistent with the Autonomy Principle.
  2. The presumption should always be in favor of treatment. This reflects the Life principle. This presumption may be overcome in the clearly specified situations enumerated in section II. D.2. above. Withholding or withdrawal of nutrition and hydration may be allowed in these situations, but is generally not allowed in all other situations.
  3. Persons in a "minimally conscious state" are not at the end of life as defined above. Withholding or withdrawal of life-sustaining treatment (including nutrition and hydration) is not permissible unless the person has previously expressed a clear and competent preference regarding such withholding or withdrawal. AAIDD believes that determination of the person's previously expressed preferences should follow the legal standard of "beyond a reasonable doubt" in this situation.
  4. The legally determined next of kin (parent, spouse, etc.) or court-appointed guardian is authorized to make treatment decisions when the person is not able to make these decisions directly.
  5. Judicial review is appropriate and necessary when application of this policy is unclear or in dispute among health care providers, family members, guardians, friends and other significant caregivers.

B. Physicians should always act in conformity with existing codes of medical ethics, existing state and federal laws, and their conscience.

1. Physician-assisted suicide (PAS) is opposed by the American Medical Association and is illegal in nearly all states. Physicians must not provide PAS to persons with intellectual or developmental disabilities in states where it is illegal to do so. Where it is legal, physicians must follow the legally-specified procedures in their jurisdiction. Application of those procedures must also be consistent with the principles outlined above. Even if it is legal, physicians cannot be compelled to provide PAS if it is against their conscience to do so.
2. Active voluntary euthanasia is different from PAS and is illegal everywhere in the United States. In PAS, a physician provides a fully competent person with the means to terminate his or her own life. In active voluntary euthanasia, the physician or some other agent terminates the person's life directly. Active voluntary euthanasia is never permissible.
3. Individuals choosing PAS must be legally competent, where this procedure is legal. Surrogates cannot choose PAS for another person. Any attempt by another person (such as a parent or health care provider) to choose PAS for a person with intellectual or developmental disabilities is not permissible.

C. Public policy should be developed to reflect the principles enumerated above.

IN THE DISTRICT COURT OF \_\_\_\_\_ COUNTY  
STATE OF OKLAHOMA

IN THE MATTER OF THE GUARDIANSHIP )  
OF \_\_\_\_\_, An )  
Incapacitated Adult. )

Case No. PG- \_\_\_\_\_ - \_\_\_\_\_

PLAN FOR THE CARE AND TREATMENT OF THE WARD

I, \_\_\_\_\_, the Guardian for \_\_\_\_\_  
who is residing at \_\_\_\_\_,  
hereby submit this [ ] initial [ ] annual Guardianship Plan for the care and treatment  
of said ward.

1. I believe the services necessary for the physical health and safety of the ward are as follows:

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_.

2. Those services will be obtained or provided as follows:

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_.

3. The decisions as to the care and treatment of the ward will be shared with the Guardian of the Property, if a separated Guardian of the Property has been appointed, otherwise I will make all such decisions consistent with the Orders of this Court.

4. I believe the following services will assist in the fulfilling of the needs of the ward, implementing the terms of the Orders of this Court.

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_.

Executed this \_\_\_\_\_ day of \_\_\_\_\_, 20\_\_\_\_.

\_\_\_\_\_  
Guardian

Address: \_\_\_\_\_

\_\_\_\_\_  
Telephone #: ( ) \_\_\_\_\_

IN THE DISTRICT COURT OF \_\_\_\_\_ COUNTY  
STATE OF OKLAHOMA

IN THE MATTER OF THE GUARDIANSHIP )  
OF \_\_\_\_\_, An )  
Incapacitated Adult. )

Case No. PG- \_\_\_\_\_ - \_\_\_\_\_

PLAN FOR THE MANAGEMENT OF THE PROPERTY OF THE WARD

I, \_\_\_\_\_, the Guardian for \_\_\_\_\_  
who is residing at \_\_\_\_\_,  
hereby submit this [ ] initial [ ] annual Guardianship Plan for the care and treatment  
of said ward.

1. I believe the services necessary for the management of the property of the ward  
are as follows:

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_.

2. Those services will be obtained or provided as follows:

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_.

3. The decisions as to the management of the property of the ward will be shared with the  
Guardian of the Person, if a separate Guardian of the Person has been appointed, otherwise I  
will make all such decisions consistent with the Orders of this Court.

4. I believe the following services will assist in the fulfilling of the needs of the ward,  
implementing the terms of the Orders of this Court.

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_.

Executed this \_\_\_\_\_ day of \_\_\_\_\_, 20\_\_\_\_\_.

\_\_\_\_\_  
Guardian

Address: \_\_\_\_\_

\_\_\_\_\_  
Telephone #: ( ) \_\_\_\_\_

IN THE DISTRICT COURT OF \_\_\_\_\_ COUNTY  
STATE OF OKLAHOMA

IN THE MATTER OF THE GUARDIANSHIP )  
OF \_\_\_\_\_ )  
\_\_\_\_\_ )

Case No. PG- \_\_\_\_\_ - \_\_\_\_\_

REPORT ON THE GUARDIANSHIP OF THE PERSON

I, \_\_\_\_\_, the (Guardian/Limited Guardian of the person)  
(Name)

for \_\_\_\_\_  
(Name)

an (incapacitated/partially incapacitated) person, hereby submit this (annual,  
court-ordered) Guardianship Report.

1. The present place of abode of the ward is: \_\_\_\_\_  
\_\_\_\_\_

2. The type of home or facility in which the ward lives is: \_\_\_\_\_  
\_\_\_\_\_

and the name of the person in charge of the home or facility is: \_\_\_\_\_  
\_\_\_\_\_

3. My present street address and telephone number are:  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

4. During the last year, I have seen the ward \_\_\_\_\_ times. I otherwise or also  
have become or remained familiar with the needs and care of the ward as follows:  
\_\_\_\_\_  
\_\_\_\_\_

The nature of my visits to the ward have been: \_\_\_\_\_  
\_\_\_\_\_

5. The following services are currently being provided to the ward: \_\_\_\_\_  
\_\_\_\_\_

6. These services (are, are not) provided for in the current Guardianship Plan.  
The reason they are not shown in the current Guardianship Plan is: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_
7. The ward was last seen by a physician on: \_\_\_\_\_  
The purpose of the visit was: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_
8. I (have, have not) observed any major change in the ward's physical or mental condition during the last year. (If so,) these are my observations: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_
9. I (have, have not) taken any significant action for or on behalf of the ward since the last time I submitted a Guardianship Report. (If so,) I took the following actions: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_
10. There (have, have not) been any significant problems relating to the ward or to my guardianship of the ward since the last time I submitted a Guardianship Report. (If so,) I have observed these problems: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_
11. It is my opinion that the guardianship (should, should not) be continued. (If so,) the basis for my belief is as follows: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_
12. I believe the ward (would, would not) be able to manage essential requirements for physical health and safety with fewer restrictions on the ward's ability to act for himself/herself. (If so,) the basis for my belief is as follows: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

13. My opinion of the present care being provided to the ward is as follows: \_\_\_\_\_

14. The place of abode of the ward (has, has not) changed since the last guardianship report.  
(If so,) the place of abode of the ward was changed for the following reasons:

I hereby swear that the answers set forth above are true and correct to the best knowledge and belief of the undersigned, subject to the penalties of making a false affidavit or declaration.

\_\_\_\_\_  
Date

\_\_\_\_\_  
(Signature of Guardian/Co-Guardian)

\_\_\_\_\_  
(Signature of Co-Guardian)

\_\_\_\_\_  
(Signature of Co-Guardian)

\_\_\_\_\_  
(Telephone)

Attachments (if relevant):

1. An accounting of any monies received by the Guardian or Limited Guardian on behalf of ward.
2. Any expenditures made by the Guardian or Limited Guardian on behalf of the ward.
3. Any compensation requested by the Guardian or Limited Guardian.
4. Copies of any appropriate medical records, evaluations, or other similar documentation pertinent to the reporting period.

IN THE DISTRICT COURT OF \_\_\_\_\_ COUNTY  
STATE OF OKLAHOMA

IN THE MATTER OF THE GUARDIANSHIP )  
OF \_\_\_\_\_ )  
\_\_\_\_\_ )

Case No. PG- \_\_\_\_\_ - \_\_\_\_\_

REPORT ON THE GUARDIANSHIP OF THE PROPERTY

I, \_\_\_\_\_, the (Guardian/Limited Guardian of the property)  
(Name)

for \_\_\_\_\_  
(Name)

an (incapacitated/partially incapacitated) person, hereby submit this (annual,  
court-ordered) Guardianship Report.

1. The present place of abode of the ward is: \_\_\_\_\_

2. The type of home or facility in which the ward lives is: \_\_\_\_\_

and the name of the person in charge of the home or facility is: \_\_\_\_\_

3. My present street address and telephone number are: \_\_\_\_\_

4. Significant changes in the capacity of the ward to manage his or her financial resources: \_\_\_\_\_

5. The following services are currently being provided to the ward: \_\_\_\_\_

6. These services (are, are not) provided for in the current Guardianship Plan.  
The reason they are not shown in the current Guardianship Plan is: \_\_\_\_\_

7. I (have, have not) taken any significant action for or on behalf of the ward since the last time I submitted a Guardianship Report. (If so,) I took the following actions: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

8 There (have, have not) been any significant problems relating to the ward or to my guardianship of the ward since the last time I submitted a Guardianship Report. (If so,) I have observed these problems: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

9. It is my opinion that the guardianship (should, should not) be continued. (If so,) the basis for my belief is as follows: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

10. I believe the ward (would, would not) be able to manage his or her financial resources with fewer restrictions on the ward's ability to act for himself/herself. (If so,) the basis for my belief is as follows: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

I hereby swear that the answers set forth above are true and correct to the best knowledge and belief of the undersigned, subject to the penalties of making a false affidavit or declaration.

\_\_\_\_\_  
Date

\_\_\_\_\_  
(Signature of Guardian/Co-Guardian)

\_\_\_\_\_  
(Signature of Co-Guardian)

\_\_\_\_\_  
(Telephone)

**Attachments (Required):**

1. Complete financial statement of the financial resources of the ward under the control or supervision of the Guardian or Limited Guardian of the property.
2. An accounting of any receipts and disbursements received, or expenditures made by the Guardian or Limited Guardian on behalf of the ward.

**Attachments (Optional):**

1. Request for compensation for Guardian.
2. Request for compensation for attorney for the ward.

IN THE DISTRICT COURT OF \_\_\_\_\_ COUNTY  
STATE OF OKLAHOMA

IN THE MATTER OF THE GUARDIANSHIP )  
OF \_\_\_\_\_, An )  
Incapacitated Adult. )

Case No. PG- \_\_\_\_\_ - \_\_\_\_\_

NOTICE OF HEARING ANNUAL REPORT OF GUARDIAN

TO: ALL PERSONS RECEIVING NOTICE OF THE ANNUAL REPORT ON THE GUARDIANSHIP  
OF \_\_\_\_\_ (name of ward):

You are notified that the enclosed Annual Report on the Guardianship of the Person and  
Property of \_\_\_\_\_ (name of ward) was filed with the  
District Court of \_\_\_\_\_ County, Oklahoma, on \_\_\_\_\_  
(date Annual Report filed - month-day/year), and is given to you as required by law.

You are entitled to object to any items contained in the annual report within 15 days from its  
filing with the Court. If no objections to the annual report are filed within the 15 day period,  
the annual report will be approved by the Court including the payment of the guardian fee and  
attorney's fee if applicable.

Dated this \_\_\_\_\_ day of \_\_\_\_\_, 20\_\_\_\_\_.

\_\_\_\_\_  
Guardian or Judge's signature

\_\_\_\_\_  
GUARDIAN

\_\_\_\_\_  
ADDRESS

\_\_\_\_\_  
TELEPHONE

IN THE DISTRICT COURT OF \_\_\_\_\_ COUNTY  
STATE OF OKLAHOMA

IN THE MATTER OF THE GUARDIANSHIP )  
OF \_\_\_\_\_, An )  
Incapacitated Adult. )

Case No. PG- \_\_\_\_\_ - \_\_\_\_\_

ORDER APPROVING ANNUAL REPORT

Now on this \_\_\_\_\_ day of \_\_\_\_\_, 20\_\_\_\_, to \_\_\_\_\_, 20\_\_\_\_, on the Guardianship of the Person of the above-named Ward, having been presented to the Court for approval, and the Court having reviewed the Annual Report submitted by the Guardian along with the Guardianship Plan.

**FINDS, ORDERS, ADJUDGES AND DECREES** as follows:

1. That the Annual Report is approved as submitted.
2. That this Order Approving Annual Report is temporary in nature and will become final without any additional written order on the 16th day after the Annual Report is filed unless an objection to the Annual Report is filed during that fifteen (15) day period.
3. That the Guardian shall file the next Annual Report on or before the \_\_\_\_\_ day of \_\_\_\_\_, 20\_\_\_\_.
4. Court cost is waived pursuant to Oklahoma Title 56 Statue 192.

\_\_\_\_\_  
JUDGE OF THE DISTRICT COURT

IN THE DISTRICT COURT OF \_\_\_\_\_ COUNTY  
STATE OF OKLAHOMA

IN THE MATTER OF THE GUARDIANSHIP )  
OF \_\_\_\_\_, An )  
Incapacitated Adult. )

Case No. PG- \_\_\_\_\_ - \_\_\_\_\_

CERTIFICATE OF MAILING

The undersigned does hereby state that on the \_\_\_\_\_ day of \_\_\_\_\_, 20 \_\_\_\_, I deposited in the U.S. Mail, in \_\_\_\_\_, Oklahoma with sufficient postage thereon fully prepaid, a true and correct copy of the *Annual Report on Guardianship* and the *Notice of Hearing Annual Report of Guardian* to the following:

1. DHS/Developmental Disabilities Services Division

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

2. DHS/Developmental Disabilities Services Division

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

3.

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

4.

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

\_\_\_\_\_  
GUARDIAN

\_\_\_\_\_  
ADDRESS

\_\_\_\_\_  
TELEPHONE

# Information Sheet

---

---

Name of Person		Common Name
----------------	--	-------------

---

Address	City/State/Zip	Phone
---------	----------------	-------

---

Place of Employment	Address	City/State/Zip	Phone
---------------------	---------	----------------	-------

---

Case Manager	Address	City/State/Zip	Phone
--------------	---------	----------------	-------

---

Residential Provider	Address	City/State/Zip	Phone
----------------------	---------	----------------	-------

---

---

Names of Contact People: (Residential)	_____	Phone: _____
	_____	_____
	_____	_____

---

---

## Other Names and Numbers

---

Name	Address	City/State/Zip	Phone
------	---------	----------------	-------

---

Name	Address	City/State/Zip	Phone
------	---------	----------------	-------

---

Name	Address	City/State/Zip	Phone
------	---------	----------------	-------

---

Name	Address	City/State/Zip	Phone
------	---------	----------------	-------

---

Name	Address	City/State/Zip	Phone
------	---------	----------------	-------

---

Name	Address	City/State/Zip	Phone
------	---------	----------------	-------

---

Name	Address	City/State/Zip	Phone
------	---------	----------------	-------

---

Name	Address	City/State/Zip	Phone
------	---------	----------------	-------



## **Acknowledgements:**

We would like to thank the following persons who provided expertise, technical assistance and a great amount of time in the development and review of this handbook for DDSD guardians. This publication was the result of collaboration between DDSD staff and employees of TARC, the volunteer guardianship agency contracting with DDSD.

### **Committee Members:**

Leah Abney, DDSD, guardianship coordinator  
Aaron Brown, TARC, assistant executive director  
Marilyn Goodban, DDSD, guardianship coordinator  
Angela Kecseg, TARC, volunteer guardian coordinator  
Rebecca Palmer, DDSD, guardianship program manager  
Sheree Powell, DDSD, editor  
Jackie Prewitt, DDSD, guardianship coordinator  
Ray Gene Trimble, DDSD, guardianship coordinator

We would also like to thank Maureen Knudson, attorney at law, for contributing her time in reviewing this handbook. Knudson's expertise in guardianship for persons with developmental disabilities is greatly valued and appreciated.

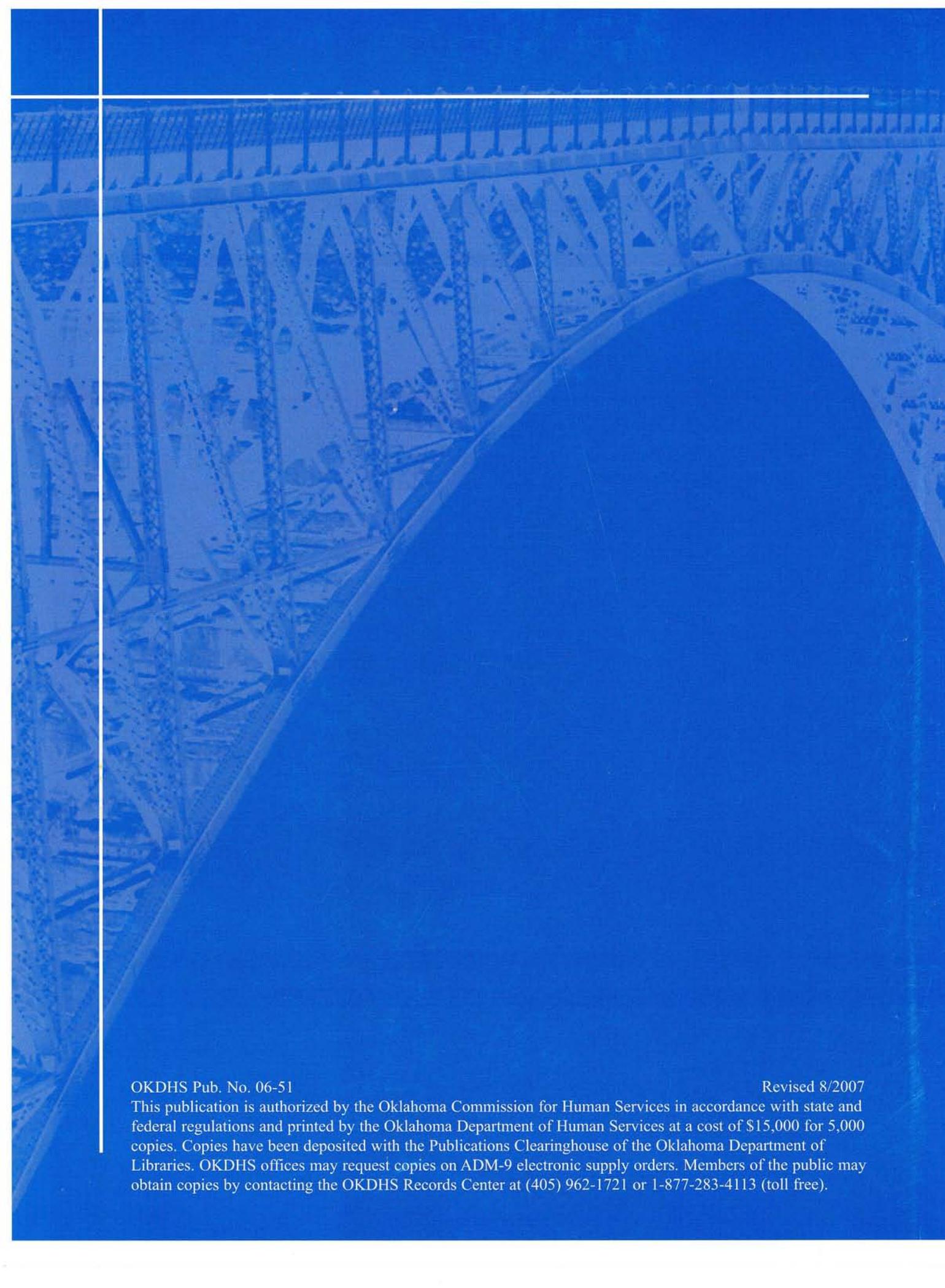
And thanks to Susan Lash, former DDSD Health Services administrator, for her valuable insight regarding the end-of-life sections. Her passion and commitment to the people she served is forever her legacy to DDSD.

The committee would like to thank and acknowledge the Florida Developmental Disabilities Council for sharing their excellent publication *Planning Ahead: A Handbook for Parents, Family Members and Guardians of Adults with Developmental Disabilities*. Much of the DDSD handbook section on *Planning Ahead* was repeated from their eloquently written publication.



JAN 30 2008

OREA PUB. CLEARINGHOUSE



OKDHS Pub. No. 06-51

Revised 8/2007

This publication is authorized by the Oklahoma Commission for Human Services in accordance with state and federal regulations and printed by the Oklahoma Department of Human Services at a cost of \$15,000 for 5,000 copies. Copies have been deposited with the Publications Clearinghouse of the Oklahoma Department of Libraries. OKDHS offices may request copies on ADM-9 electronic supply orders. Members of the public may obtain copies by contacting the OKDHS Records Center at (405) 962-1721 or 1-877-283-4113 (toll free).