

# Iowa Substitute Decision Maker Act

The Iowa Substitute Decision Maker Act was passed by the Iowa Legislature in 2005. The Act provides for the establishment of state and local offices to provide substitute decision making services to adults of all ages who might need this service. As is sometimes the case, the Legislature did not appropriate funds to help establish these offices. This packet will provide you with information about the Act and what you can do to help get the Legislature to appropriate funds for this very important service.

*This material provided to you by advocates who feel strongly that the State Legislature should fund this activity.*



**Iowa Substitute Decision Maker Act**  
**Iowa Code §231E**  
**July 1, 2005**

- Establishes state and local offices to provide substitute decision maker services to adults of all ages who might be in need of but do not have access to a guardian, conservator, representative payee, and/or an attorney-in-fact.
- Offices serve as a last resort for individuals who have no one available to serve or for individuals who might be victims of abuse or neglect at the hands of their current substitute decision maker.
- State office would be within the Department of Elder Affairs. The state office would provide training and education on substitute decision making issues as well as monitor local decision makers.
- Local entities would apply, through a Request for Proposal process, to become the local decision maker of last resort.
- The local office of substitute decision maker would serve as the least restrictive decision maker. The office could be appointed either representative payee, attorney-in-fact, guardian or conservator, after an assessment to determine the level of decision making services needed by the client.
- Safeguards against conflict of interest between the local decision maker office and the client have been built into the proposal.
- Fees may be charged for the service based upon the client's ability to pay.
- The local or state office may also serve as Personal Representative for an estate in which no one is available to start the probate process. This could assist the State of Iowa recover funds owed to Medicaid through estate recovery as well as generate income to offset costs of the program.
- The Office of Substitute Decision Maker Act does not supplant current efforts by non-profits, counties or other entities to provide decision making services. If such a service exists, then the offices would not be utilized. These offices are truly intended to serve after all other avenues have been pursued.

## **Issue Brief: Office of Substitute Decision Making**

### **What does substitute decision maker mean?**

A substitute decision maker is an individual appointed to assist someone in making financial or personal care decisions. A substitute decision maker can be a guardian, conservator, representative payee, attorney-in-fact, or personal representative.

### **What would the Office of Substitute Decision Maker do?**

It would provide substitute decision making services to Iowans age 18 and older for those who have no one or have no one appropriate to serve as their substitute decision maker.

### **Why is an Office of Substitute Decision Maker needed?**

- “Many adults in this state are unable to meet essential requirements to maintain their physical health or to manage essential aspects of their financial resources and are in need of substitute decision – making services. However, a willing and responsible person may not be available to serve as a private substitute decision maker or the adult may not have adequate income or resources to compensate a private substitute decision maker.” Iowa Code 231E.2 (1)(a).
- It creates “a process to assist individuals in finding alternatives to substitute decision-making services and less intrusive means of assistance before an individual’s independence or rights are limited.” Iowa Code 231E.2 (1)(b).
- It serves “to finalize a person’s affairs after death when there is no willing and appropriate person available to serve as the person’s personal representative.” Iowa Code 231E.2 (1)(c).

### **Will the client be responsible for the cost of these services?**

- Fees may be charged, based on the client’s ability to pay.

## Issue Brief: Office of Substitute Decision Making

### Talking Points

- 44,663 Iowans in need of a substitute decision maker were identified in a recent survey conducted by the Department of Elder Affairs.
- Iowa Code §231E establishes state and local offices to provide substitute decision maker services. It was enacted July 1, 2005, without funding; therefore it has not yet been implemented.
- Iowa is currently 1 of 6 states without a public guardianship program
- The Office of Substitute Decision Maker would:
  1. ensure that the appropriate least restrictive decision maker service is utilized;
  2. serve as the decision maker of last resort or may intervene if there is an inappropriate decision maker, and
  3. provide for training and education on substitute decision making issues.
- The Office of Substitute Decision Maker will not supplant current efforts by non-profits, counties, individuals, or other entities to provide these services.
- Many Iowans in need of substitute decision making services are unable to request or access assistance.

## Substitute Decision Making Case Examples

**In all of the examples listed below, an Office of Substitute Decision Maker, would be available to serve as the decision maker, to intervene on behalf of a victim of abuse or to educate family members about substitute decision making.**

- **Facts:** Mr. Nelson was detained in the hospital awaiting placement in a nursing home as there were no family members or anyone readily available to serve as a guardian. In addition, no one was available to assist with completing the applications for financial assistance, to verify his personal financial status or admit him into a nursing home. The Office of Substitute Decision Maker, once appointed, could move Mr. Nelson to an appropriate placement. (Case from Calhoun County)
  
- **Facts:** A long-term care facility is closing and needs to place the residents elsewhere. Many of the residents do not have the ability to make placement decisions and have no one in their lives that can serve as a substitute decision maker (power of attorney or guardian). The Office of Substitute Decision Maker could be appointed as attorney in fact or as an emergency guardian to assist with the admission paperwork to ensure that the residents remain in a safe level of care. (Case from Polk, Jasper, Muscatine and Mahaska Counties)
  
- **Facts:** A woman with dementia was brought to the hospital from her home needing work-up for possible surgery due to abdominal pain, but since this was not seen as an emergency, the physicians were not willing to accept her signature as “informed consent”. The procedures were delayed. No family member was willing to serve in that capacity. The Office of Substitute Decision Maker, if appointed, would be able to provide consent for the procedure. (Case from Iowa, Scott, Linn, Johnson and Cherokee Counties)
  
- **Facts:** Mr. Brown’s children felt that he was not making good choices for his health care and filed a guardianship petition. Mr. Brown still had the ability to make some health care choices, however. Mr. Brown’s children were granted guardianship and Mr. Brown lost all of his abilities for choice. In this case, least restrictive alternatives, such as durable power of attorney or limited guardianship were available. These alternatives would have given Mr. Brown the legal right to make decisions for himself, as appropriate. If contacted, the Office of Substitute Decision Maker could have worked with the family to educate them on the alternatives available and acted as an advocate for Mr. Brown. (Case from Polk and Story Counties)
  
- **Facts:** Two adult children were named guardian and conservator over their mother. As guardian and conservator, the children owed their mother the duty to act in her best interests. Unfortunately, that did not happen. The adult children took advantage of their mother by living in her home and using her social security funds to supplement their own income. The Guardians refused to provide needed home care services because they used their mother’s money for themselves. No annual reports have been filed with the court. The Office of Substitute Decision Maker could intervene or be appointed as a more appropriate guardian and conservator and alleviate the exploitation as the mother needed a Guardian/Conservator that would act in her best interests. (Case from Polk County)

## **THE IOWA SUBSTITUTE DECISION MAKER ACT WILL**

- **Establish state and local offices to provide substitute decision maker services to adults of all ages who might be in need of but do not have access to a guardian, conservator, representative payee, and/or attorney-in-fact under a power of attorney.**
- **Provide a uniform system and support network for vulnerable, at-risk, or incapacitated adults who have no appropriate family or friends available to help them with needed medical or financial decision-making.**
- **Prevent a medical or financial crisis caused by the lack of a substitute decision maker.**
- **Utilize existing substitute decision-making resources and develop additional resources within communities.**

### ***The Iowa Substitute Decision Makers Office will accomplish or promote the above by helping to:***

- **Protect vulnerable individuals;**
- **Prevent a medical or financial crisis or abuse;**
- **Provide the least restrictive decision maker alternative;**
- **Maximize individual autonomy and independence;**
- **Serve as a clearinghouse/contact point for availability and dissemination of substitute decision making information to consumers;**
- **Improve the availability and quality of information provided to guardians, conservators, attorneys-in-fact and other decision makers without duplicating existing programs and services;**
- **Enhance training for and oversight of substitute decision makers.**

# **Office of Substitute Decision Maker**

## **Why is funding needed?**

- To allow the Office of Substitute Decision Maker to serve individuals in need. Establishing the office through legislation in 2005 was crucial, but without funding or employees the office cannot accept referrals or contract with local programs to serve the need.
- Many frail and challenged adults, unable to make decisions, are forced into an environment and level of care that may not be needed. This costs the state thousands of dollars each year to house adults in high level of care settings when less restrictive and less costly settings would be available if a substitute decision maker was located.
- Currently, some facilities are being cited by state and federal regulators for having residents without a decision maker. The facilities are aware of the need but cannot locate persons to serve as the resident's decision maker. Due to these citations, the facilities may be in jeopardy of losing funding which would potentially displace and adversely impact the residents. The Office of Substitute Decision Maker would be a resource to assist those residents.
- The Medicare Modernization Act of 2003, Prescription Drug Benefit, becomes effective January 1, 2006. There will likely be a number of vulnerable and challenged adults who are unable to make decisions to elect a prescription drug plan and will have no one to act on their behalf. The Office of Substitute Decision Maker could assist those individuals.
- 27% of Medicare beneficiaries have some form of cognitive impairment. (Source: Academy Health's 2005 Annual Research Meeting, 6/27/05)
- A 1989, 27-county survey identified a total of 3,586 individuals in need of a substitute decision maker. The survey showed that individuals in all age groups were in need of substitute decision makers. 22% of the clients were between 18 and 35 years. However, most of the clients were older, as 22% were between ages 56-75 and 42% were age 76 and older.
- From the 1989 survey, individuals needed a substitute decision maker due to abuse and exploitation; for personal care needs; for financial management to pay bills or manage assets; to provide for a safe and harm-free living environment; and to consent to medical interventions and other health care needs.

***IOWA NEEDS SUBSTITUTE DECISION MAKING  
CHANGES BECAUSE:***

- Many adults in need of a decision maker have no one available.
- Iowa is 1 of 6 states without a public guardianship system.
- Iowa has a large elderly population and the need for a substitute decision maker increases with age.
- Adults with disabilities are outliving their family decision makers.

***ENACTMENT OF THIS LEGISLATION WILL HELP:***

- Prevent abuse, exploitation, and scams;
- Prevent loss of home or savings;
- Provide an appropriate level of care;
- Provide an advocate to protect and ensure safety;
- Provide access to needed services to those who cannot consent;
- Provide alternatives to inappropriate or poor decision makers; and
- Provide planning for incapacity.



**Results from Electronic Substitute Decision Maker  
Survey  
September to December 2005**

Total responses: 232

**Question: How many clients are in need of a decision maker?**

177 responses

- 158 Clients are in need
- 3 Clients are in need but gave % (10%; 25%; 50%)
- 1 Unknown
- 1 Have program in place
- 13 No clients in need
- 1 Contact me

When asked how many (exact numbers) clients are in need, the 158 identified **44,663** individuals in need of a substitute decision maker

**Question: How many clients in need have no available or appropriate family members or friends to serve as guardian or conservator?**

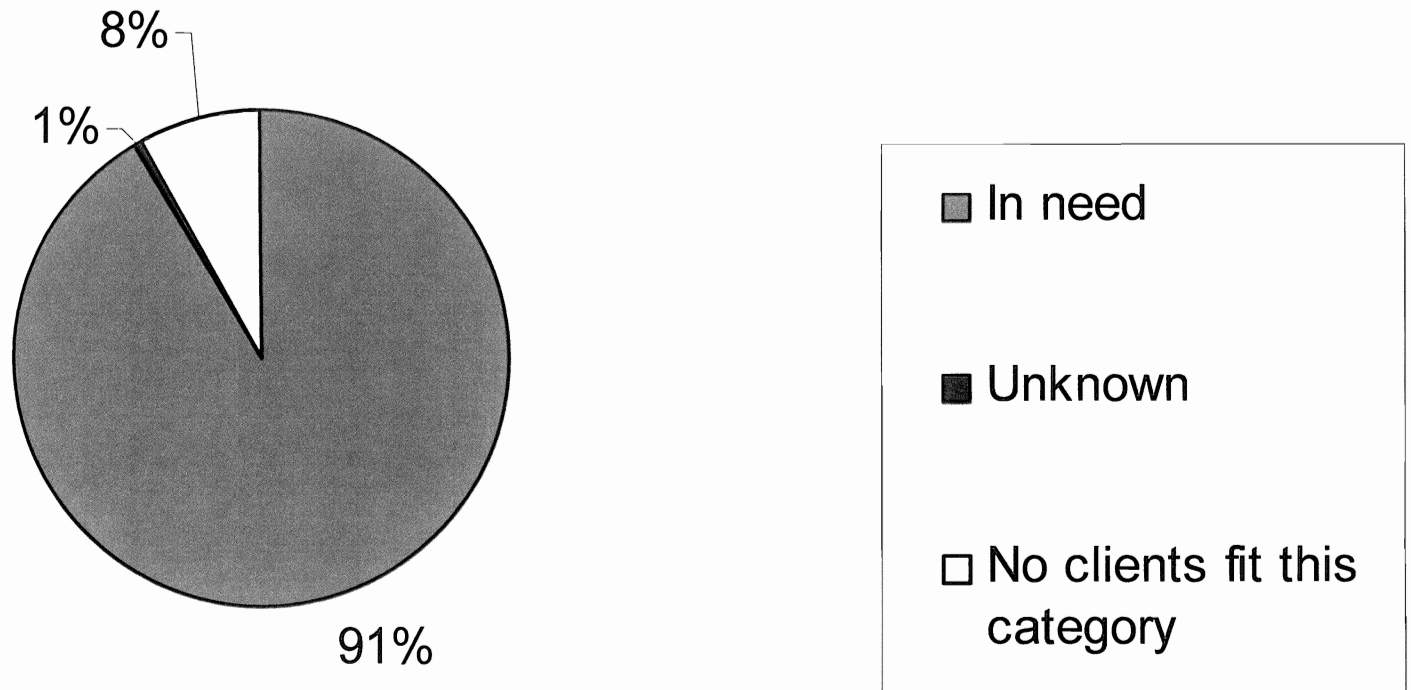
223 responses

- 188 Clients need a guardian/conservator and have no one
- 6 Clients need a guardian/conservator and gave %  
(1/2 to 3/4; 10%; 30%; 40%; 50%; 95%)
- 22 No clients fit this category
- 1 Many
- 1 Several
- 1 Varies
- 2 Unknown
- 2 Very few

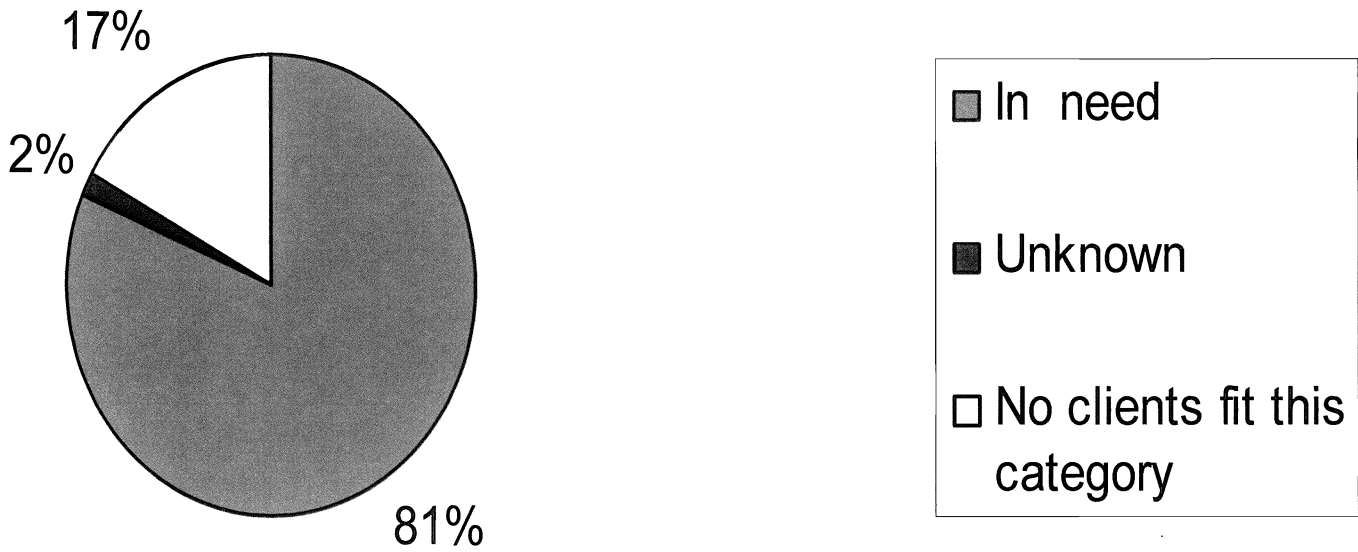
When asked how many clients needed a guardian or conservator and had no one to serve, the 188 responses identified **19,188** clients in need.

# Results from Substitute Decision Making survey September—December 2005

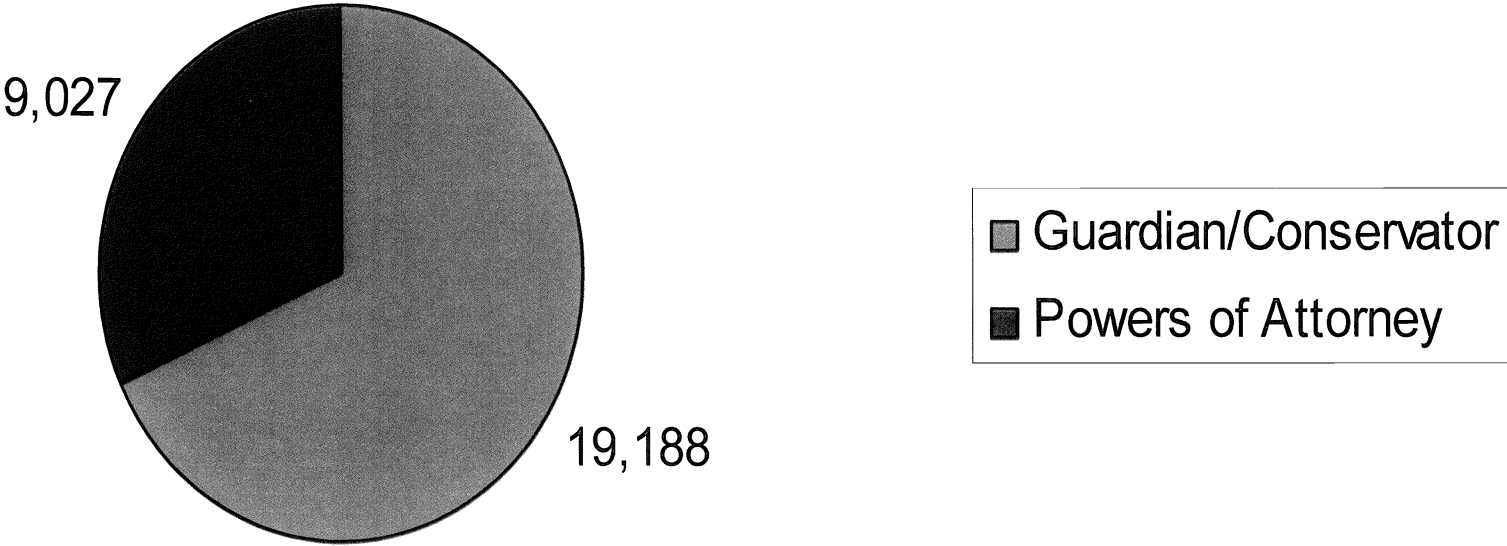
## Participants Identifying Clients in Need of a Decision Maker



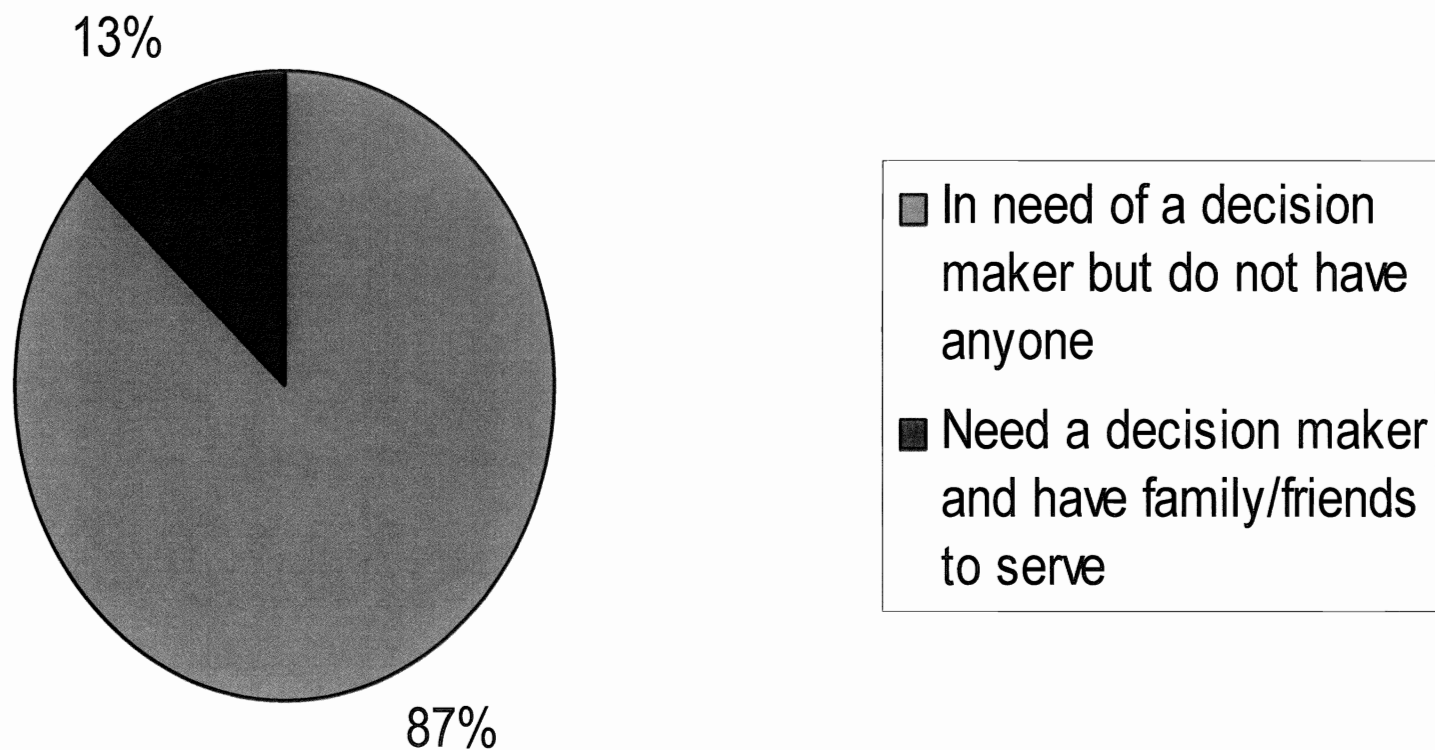
# Participants Identifying Clients Who Are in Need and Have No Appropriate Family Members or Friends to Serve as a Decision Maker



# Clients Needing a Decision Maker with No Family or Friends

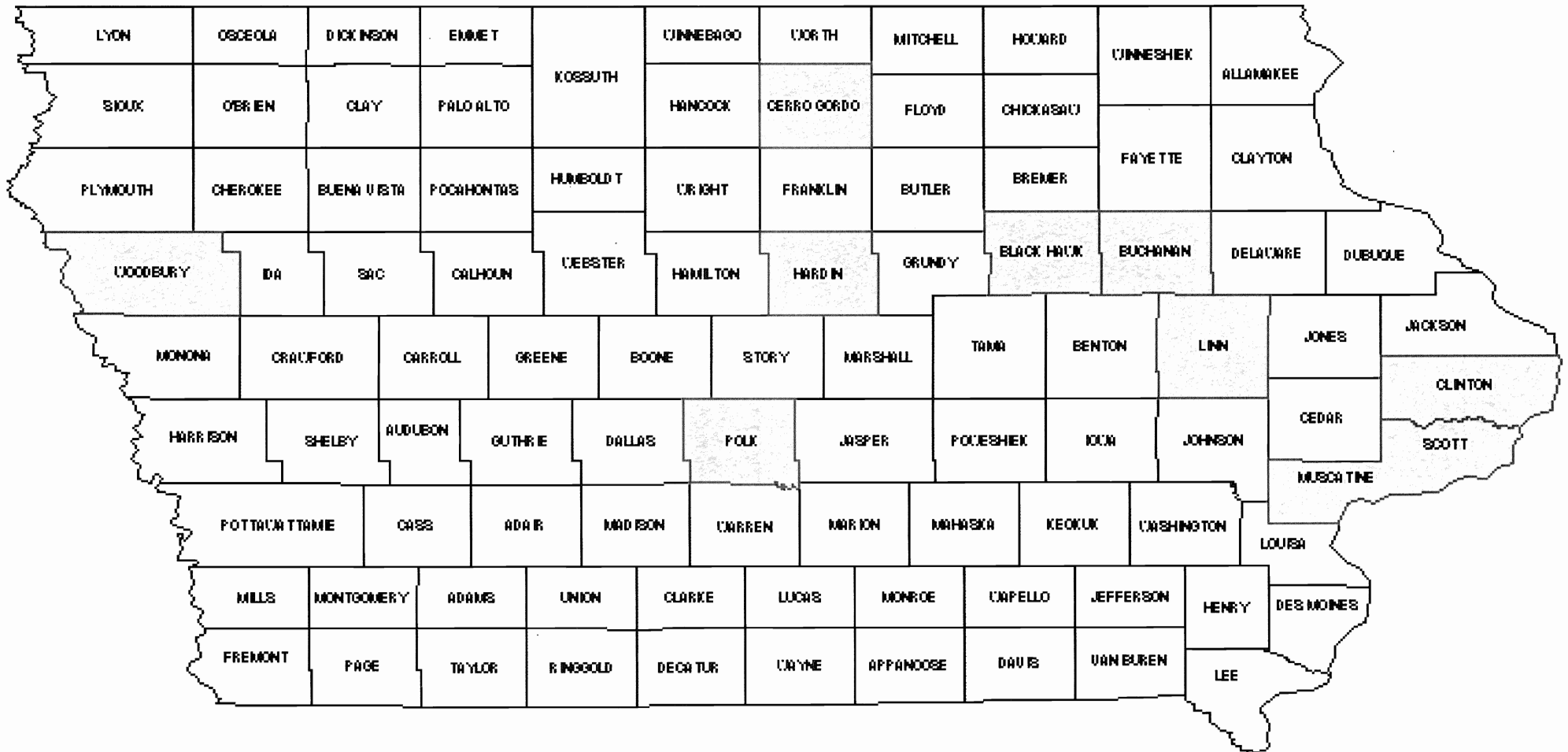


## Client Decision Maker Needs: Met vs. Unmet



# Comprehensive Guardian and Conservator Programs in Iowa

A comprehensive program serves 5 or more individuals



All programs have eligibility restrictions. See Exhibit A

## Comprehensive Guardianship and/or Conservatorship Programs in Iowa

Programs or individuals serving 5 or more clients  
Exhibit A--September 14, 2006

Program	Location	Current Clients Served	Criteria
Black Hawk County Conservator's Office	Waterloo	26 Guardianship 15 Conservatorship 17 Guardian/Conservator 33 Payee 17 Guardian/Payee 108 total Clients served	Guardianship, Conservatorship & Payee Indigent elderly and disabled Serve Black Hawk County residents only Office staff --assisted families to establish
Center for Siouxland	Sioux City	122 Conservatorship 17 Guardianship 139 total Clients served	No longer offer guardianship services Provide conservator or payee services only Serve NW and Western Iowa
Community Supports Department	Clinton	20 Guardianship	Serve Clinton County residents Serve as last resort only
Dirksen, Bev Guardian Angel Services	Iowa Falls	2 Guardianship 2 Conservatorship 1 Guardian/Conservator 5 total Clients served	Guardianship and Conservatorship Private -hourly fee
Iowa Guardianship Incorporated	Clear Lake	18 current guardianships 23 enrolled individuals 41 total to be served	Guardianship only Served by volunteer monitors Lifetime fee arrangement Most clients --served by Opportunity Village

Muscatine County Community Services	Muscatine	26 Guardianships 17 Conservatorships 151 Payee 194 total Clients served	60 or older Apply for and be approved for service through Muscatine Co. CPC Utilize volunteers for guardianship program
Permanent Planning Incorporated	Waterloo	56 current Guardianships 35 enrolled individuals 91 total to be served	Guardianship only Lifetime fee arrangement Primary Diagnosis of mental retardation Reside or legal settlement-Black Hawk Co.
Polk County Attorney's Office	Des Moines	725 Guardianships 75 G'ship/Conservatorships 800 total Clients served	Guardianship & Conservatorship Utilize volunteers and family members For DHS clients only
Scott County Community Services	Davenport	9 Guardianships 8 Conservatorships 435 Payees 442 total Clients served	Referrals from DHS or Social Security only For Scott County residents only Fees charged for payee
The Heritage Agency	Cedar Rapids	6 Guardian/Conservatorships	Client must be a victim of abuse and part of the Elder Abuse Initiative Attorneys serve as decision maker Serve Linn and Johnson Counties only
Tonn, Billie Jo	Independence	9 Guardianships	Guardianships only Referrals from county case mgmt



## **Organizations formally supporting funding for the Substitute Decision Maker Act—Iowa Code §231E**

- **AARP**
- **Aging and Disability Coalition for Community First**
- **Drake Legal Clinic**
- **Governor's Developmental Disabilities Council**
- **Iowa Association of Area Agencies on Aging**
- **Iowa Association of Community Providers**
- **Iowa Commission on the Status of Women**
- **Iowa Department of Elder Affairs Commission**
- **Iowa Department of Human Services Council**
- **Iowa Department of Public Health**
- **Iowa Dependent Adult Protective Advisory Council**
- **Iowa Psychiatric Society**
- **Iowa State Bar Association**
- **Senior Living Coordinating Unit**

**Budget to implement Iowa Code §231E, Substitute Decision Maker Act  
2007**

**Request: \$635,126**

**Expense Description:**

**1. Establishment of state program**

- Wages (1.5 staff) \$94,026
- Office space and support (phone, equipment) \$34,800
- Travel-conduct monitoring and trainings \$10,200
- Educational materials (brochures, training materials) \$16,000
- Other expenses (publications, fees) \$ 500

**Total cost for the state office**

**\$155,526**

**2. Establishment of two local community demonstration programs**

- Community support-wages, office, operating expenses \$164,800
- Legal fees (professional fees for legal work) \$ 60,000
- Care plan services for clients \$ 15,000

**Total for one local program**

**\$239,800**

**Total for second local program**

**\$239,800**

***Total Cost for state program and 2 local programs***

**\$635,126**

## Public Guardianship

## Legal Assistance Programs

Developing a public guardianship program to assist older Iowans to receive the decision making and legal help they need and seek additional funds for legal assistance programs.

### What is being done?

- Work continues with Substitute Decision Maker Task Force-partners: AARP, Aging Resources of Central Iowa, Attorney General's Office, Bar Association, DD Council, Department of Elder Affairs, Department of Human Services, Department of Public Health, Drake University Legal Clinic, Iowa Association of Area Agencies on Aging, Iowa Association of Community Providers, Iowa Association of Homes and Services for the Aging, Iowa Hospital Association, Iowa Long-Term Care Ombudsman Office, Iowa Medical Society, Iowa State Association of Counties, Permanent Planning Incorporated, Polk Co. Attorneys Office, Private Attorneys, Scott Co. Community Services, Social Security Administration, The Heritage Agency, University of Iowa, and other county based programs. It has:
  - conducted a review of other states' laws;
  - drafted legislation and budget—231E;
  - drafted supporting documentation;
  - pulled together case examples, and
  - conducted surveys to determine the need for substitute decision making services.
- AoA grant has allowed the Task Force to lay the foundation for the program by:
  - developing tools to implement & monitor services;
  - developing training tools—modules through a Request for Proposal (RFP);
  - developing personnel training guides;
  - delivering public awareness education through:
    - trainings;
    - forums-June through August.
  - facilitating an advisory council, and by
  - ongoing presentations.

### The gaps

- Iowa is 1 of 6 states without some form of public guardianship program.
- This means that individuals in need of a substitute decision maker have very few options—if any.
- We have a piece meal approach throughout the state (Medical Substitute Decision Maker Board, DHS volunteer program and counties or entities who know of the need and have funded a county program and/or charge clients for the service).

- Of the 99 counties, 10 counties have individuals or entities that will serve as a decision maker of last resort. These individuals/entities, for our survey, were defined as programs if they served 5 or more individuals. All of the “programs” have eligibility and service provision restrictions.

### **Actions Steps**

- Implementation of a statewide and uniform system of substitute decision making for individuals who need a decision maker but have no one available, appropriate or willing to serve. Implementation will take funding
- Work with the Bar Association to update the Guardianship handbook

### **Funding needed and possible sources**

- State appropriation---assist citizens who have no one, who might otherwise end up in an abusive or exploitative situation while ensuring that their rights are protected and their independence maximized. In addition, a decision maker could assist people to receive the appropriate level of care, while utilizing his/her resources rather than turning to Medicaid.
- Grants are a possibility to assist with the program but to ensure a fully functioning program; the program would need to rely upon a reliable stream of income.
- Fee for service-clients who could afford to pay would be charged on a sliding fee scale.
- Fee for serving as representative payee for SSA/VA.
- Receive a fee for completing personal representative services for individuals who have property to probate but no one to start the process.
- Had proposed a registry through the Secretary of States’ office for registering powers of attorney. This fee would generate revenue for the Office of Substitute Decision Maker.
- Fee for conducting trainings on the topic of guardianship, conservatorship, and powers of attorney may help to fund the service.

### **Budget Proposal:**

Office and 2 local programs:

\$635,126 = (State-\$155,526) (Local-\$239,800) (Local-\$239,800)

## Substitute Decision Making Terminology

**Advance directives:** a general term for legal documents (such as a living will and a durable power of attorney for health care) that states a person's wishes for medical treatments in case he or she is not able to make his or her own decisions.

- a. **Durable power of attorney for health care:** a document authorizing an attorney in fact to make health care decisions for the principal if the principal is unable, in the judgment of the attending physician, to make health care decisions.
- b. **Living will:** a document directing that life-sustaining procedures be withheld or withdrawn if the individual's condition is determined to be terminal and the individual is not able to make treatment decisions.

**Attorney in fact:** an individual who is designated by a power of attorney document to make health care and/or financial decisions on behalf of a principal and has consented to act in that capacity.

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

**Guardian:** a person appointed by the court to have the custody of the person of the ward.

**Principal:** a person age 18 or older who has executed a durable power of attorney for health care.

**Power of Attorney:** a written document by which one person gives another person the authority to act on the first person's behalf for financial and/or health care decisions.

**Representative Payee:** an individual appointed by a federal benefit agency, such as the Social Security Administration, to manage another's federal benefit(s) checks.

**Substitute decision making:** assistance that becomes necessary when someone needs help making financial or personal care decisions.

**Ward:** an individual determined by the court to be in need of a guardian or conservator.

## **Substitute Decision Making Laws in the Iowa Code**

### **Conservatorship and Guardianship**

Iowa Code §135.28-.29 (2005) Department of Public Health “State and Local Medical Decision Making Boards”

Iowa Code §135C.24 (2005) Health Care Facilities—“Personal Property or affairs of patients or residents”

Iowa Code §217.13 (2005) Department of Human Services—“Department to provide certain volunteer services—volunteer liability”

Iowa Code §217.40 (2005) Department of Human Services—“Training for Guardians and Conservators”

Iowa Code §222.34 (2005) Persons with Mental Retardation—“Guardianship Proceedings”

Iowa Code §229.27 (Supplement 2005) Hospitalization of Persons with Mental Illness—“Hospitalization not to equate with incompetency—procedure for finding incompetency due to mental illness”

Iowa Code §231E (Supplement 2005) Substitute Decision Makers Act

Iowa Code §235B.19 (Supplement 2005) Dependent Adult Abuse—Appointment of a temporary conservator

Iowa Code §633.551, et seq. (2005) Probate Code—“Guardianships and Conservatorships general provisions”

### **Powers of Attorney**

Iowa Code §144B (2005) Durable Power of Attorney for Health Care

Iowa Code §558.36 (2005) Conveyances—“Attorney in Fact”

Iowa Code §597.5 (2005) Husband and Wife—“Attorney in Fact”

Iowa Code §633B (Supplement 2005) Probate Code-Powers of Attorney