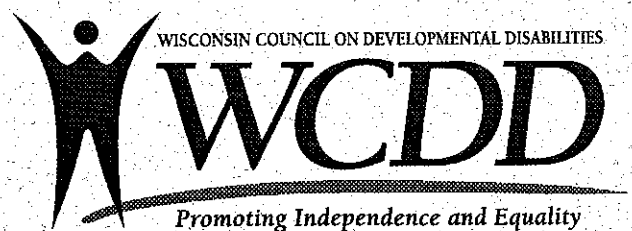


Wisconsin Council on Developmental Disabilities

Making a Difference

Thinking About Decision-Making
Support in the Transition Process

Roy Froemming, J.D.



Making a Difference:

Thinking About Decision-Making Support in the Transition Process

Roy Froemming, J.D.

July 2002

COMMUNITY SUPPORTED LIVING SERIES

SERIES EDITORS: HOWARD MANDEVILLE AND MARCIE BROST

This publication is one in a series on community supported living for people with developmental disabilities. Copies of this document and other titles in this series are available from WCDD. This paper was written and published with funding from the Wisconsin Council on Developmental Disabilities, using federal funds provided under PL 106-402 through a grant authorized by the US Department of Health and Human Services and Administration on Developmental Disabilities. WCDD encourages its project partners to freely express their findings and conclusions. The findings and conclusions in this paper do not represent WCDD's position or policy. WCDD presents this information to meet, in part, its self-determination objective set forth in the WCDD State Plan on Developmental Disabilities.

ACKNOWLEDGMENTS

This paper draws on experience in 1999-2001 working with two local efforts to promote greater self-determination of people under guardianship: the Sauk County Guardianship Work Group and the Dane County Guardianship Project Advisory Committee, and on conversations with people in other counties and states. It incorporates comments from several reviewers, including Howard Mandeville, Patricia Kelly and Jane Raymond.



Wisconsin Council on Developmental Disabilities
600 Williamson Street PO Box 7851 Madison WI 53707-7851
Voice 608/266-7826 FAX 608/267-3906 TTY/TDD 608/266-6660
Email *hfswiswcdd@dhfs.state.wi.us Webpage www.wcdd.org

Table of Contents

<u>Introduction.....</u>	4
<u>1) Start from the position that fundamental rights to liberty and pursuit of happiness require that every person have a central role in making decisions that affect his or her life...</u>	5
<u>2) Recognize that the ability to make decisions and exercise rights is a functional skill, not a medical diagnosis or legal status.....</u>	6
<u>3) Think and talk about decision-making support in the transition process, and in development of individual education plans and family support plans.....</u>	8
<u>4) Recognize the tendency to err on the side of overuse of power to make decisions for others, and the costs of over-protection.....</u>	10
<u>5) Recognize the valid purposes of decision-making support, and recognize guardianship as only one of many ways to provide decision-making support.....</u>	11
<u>6) Recognize that guardianship is not an extension of parenthood: it is an exercise of governmental power, subject to constitutional limitations.....</u>	12
<u>7) Teach the basic concepts of self-determination and self-advocacy: people have a central role to play in deciding what their lives should be like, and in planning and working to meet their goals.....</u>	13
<u>8) Develop an individualized plan for development of decision-making skills and provision of decision-making support as part of a person-centered planning process.....</u>	15
<u>9) Identify decisions that may need to be made, and the kinds of support that may help..</u>	15
<u>10) Include teaching of communication and decision-making skills in the Individual Education Plan, to be taught in the context of meaningful, real-life decisions.....</u>	17
<u>11) If guardianship is being considered, make a plan for how this particular guardian will carry out his or her responsibilities for this particular person, in line with guiding principles that reflect community expectations.....</u>	17

Introduction

Traditionally, professionals have advised parents whose sons and daughters have cognitive disabilities to seek guardianship before or soon after their child's 18th birthday. In many cases, this has been the only discussion of the issue of decision-making control and decision-making support to take place in the process of planning the child's transition to his or her role as an adult member of our society. From that point on, the process of working with the person and family to decide what role guardianship should play in the person's life has been largely left to lawyers, doctors and courts.

The result of this pattern has been a major overuse of guardianship. More people have guardians than need them. In the vast majority of cases—over 90% in one study—those who have guardians have full guardians, with no legal rights to make decisions left to the person. Even where the person retains some rights, the rights retained tend to be those listed on the court forms: voting, marriage, holding licenses, and making contracts. Basic human rights, like the rights to go where the person wants, to choose his or her own friends, and to be alone in privacy with other people, are not even discussed as part of the process. This pattern has major costs, in terms of our basic concepts of human liberty, in terms of the person's ability to develop to their full potential, and in terms of the extent to which decisions made reflect the preferences, hopes and dreams of the person whose rights the guardianship is supposed to protect.

This paper is about steps that everyone involved in the transition process—the person, family, school staff, county staff, and others who know the person well—can take to make a difference in how our society plans for and provides assistance to people who may have needs for support in making decisions and in identifying and exercising rights. As part of this process, guardianship should be seen as one form of decision-making support that, because of the legal authority it gives to another person, carries both special dangers and special opportunities.

For at least some rights of some people, making a right meaningful may require that another person be appointed who has the legal authority to get information about the person's situation and to speak on his or her behalf. In my experience, guardians act as protectors of rights that would otherwise have been lost more often than they act as oppressors who prevent the person's voice from being heard. This does not excuse us from acting to ensure that each person's voice is heard and respected. However, it should make us think carefully about each person's situation before deciding whether a particular guardianship will suppress or enhance that voice.

Guardianship should never be the only form of decision-making support. No plan for decision-making support should ever exclude the person from a central role in decisions affecting his or her life, although how that role is played will be different for different people.

- 1) **Start from the position that fundamental rights to liberty and pursuit of happiness require that every person have a central role in making decisions that affect his or her life.**

We have a shared view of the rights and responsibilities of adult citizens¹ in our society. The following statements, drawn from the Wisconsin Constitution, and from a leading Wisconsin Supreme Court case on rights of people under guardianship, apply to all members of our society, regardless of mental disability:

- “All people are born equally free and independent, and have certain inherent rights; among these are life, liberty and the pursuit of happiness ...”²
- There is a “common law right to self-determination,” under which “no right is held more sacred, or is more carefully guarded..., than the right of every individual to the possession and control of his own person, free from all restraint or interference of others, unless by clear and unquestionable authority of law.”³

Liberty, at its heart, means a central role in making the decisions that affect one’s life. We value the right to make our own decisions for its own sake, apart from the results of our decisions. Our decisions have value to us because they are ours; decisions imposed by others are denials of this basic value, even if those decisions may be “better” in other ways.⁴

Pursuit of happiness means freedom to choose and pursue our own goals, and to take risks in doing so. Again, as with liberty, we value the right to pursue happiness, apart from whether we actually achieve it. Putting pursuit of happiness at the center of planning helps to keep focus on what the person values, rather than on a set of standard systemic goals, or on the interests of others in taking the path of greatest convenience and predictability.

We cannot support a person to have control of his or her life if we do not work with the person to figure out what kind of life he or she wants. We cannot support a person to pursue happiness unless we make an effort to find out what he or she believes would bring happiness. A person will never learn what true citizenship means if he or she makes no decisions, or if those decisions have no impact on his or her life. It will help us to keep the person at the center of decision-making if we keep the following principles in mind:

- Every person has preferences, hopes and dreams. These are always the starting-place for decisions affecting the person’s life.

¹ The word “citizen” is used here in the broad sense of a member of the community; it is intended to include people who live in the United States whether or not they have U.S. citizenship.

² Art. 1, sec. 1, Wisconsin Constitution

³ *In the Matter of the Guardianship of L.W.*, 167 Wis. 2d 53 (1992)

⁴ Jan Ellen Rein. *Preserving Dignity and Self-Determination of the Elderly in the Age of Competing Interests and Grim Alternatives*. 60 Geo. Wash. L. Rev. 1827 (1992).

- Every person can learn that he or she can make a difference in the world, and that his or her opinions are worthy of respect.
- Every person can develop greater skills in understanding how decisions affect his or her life, and in communicating what he or she wants.
- The central issue in supporting the person to participate in making decisions is not the ability of the person, but the ability of the rest of us to:
- Help the person understand life choices.
- Discern the person's preferences, hopes and dreams.
- Act in ways that show that the person's opinions make a difference.

This does not mean that people providing support in decision-making must ignore threats of abuse, or must watch passively while a person who does not understand the consequences engages in unsafe conduct. Freedom from abuse (including physical, sexual and psychological abuse, unnecessary restraint and unauthorized medication), neglect, and exploitation are among the rights we should be trying to protect. However, protection from harm must be balanced against the right we all have to take risks in pursuit of our personal goals, and to learn from the consequences. "Competence" is not an all-or-nothing skill. The more the person has a clear goal and understands the risks of a decision or action, the more respect must be given to his or her right to take those risks. This need to balance conflicting rights is contained in the statement of policy in sec. 55.001, Wis. Stats., which requires that courts, counties, and guardians, in providing protective services and guardianship, must try as far as possible to:

- Allow the individual the same rights as other citizens.
- Place the least possible restriction on personal liberty and exercise of constitutional rights.
- At the same time, protect the individual from exploitation, neglect, abuse and degrading treatment.

2) Recognize that the ability to make decisions and exercise rights is a functional skill, not a medical diagnosis or legal status.

Making decisions that affect our lives, and exercising our rights as citizens, are functional skills. The effectiveness of a person's ability to make decisions will depend on four major factors:

- The person's innate ability to take in and use information, and to communicate his or her wishes.
- A base of life experience from which the person can predict and understand consequences.
- Practice in making decisions, and seeing the results.
- Amount and quality of assistance (or interference) from others.

Only the first of these factors relates to the person's cognitive ability and mental health status. The other three relate to how support is provided in the person's life, and are similar to issues that individuals, families, teachers, and human service professionals,

deal with in deciding how to meet a person's functional needs while at the same time trying to help the person develop functional skills. Too little help may leave the need unmet, while too much may leave the person in permanent over-dependence.

Despite this similarity to other functional needs and skills, planning for decision-making support for people with substantial cognitive impairments has historically been treated differently than planning for skill-development and support in other major life skill areas. Typically, both the schools and community support systems do little more than tell families of people with significant cognitive impairments that they need to consider guardianship for the person, and refer them to booklets or other sources of information. Planning of guardianship is then seen as separate from both the person's education plan and the plan for support to enable the person to have a life in the community. Guardianship is planned (if at all) by lawyers, doctors, courts, and (in some cases) protective service workers—primarily professionals in legal, medical and protective services who have, at best, only limited and short term contact with the person whose rights are at stake. It is not surprising that this pattern results in:

- Evaluations that are little more than diagnoses and blanket statements that the person needs help to meet his or her needs, that are not broken down by the type of decision the person is or is not able to make, and that provide no analysis of the impact of taking those decisions away from the person.
- Petitions for guardianships that ask for transfer of all or most powers and rights to the guardian, with little relation to the individual's life, ability to make decisions in particular areas, or capacity to learn.
- Court orders that rubber-stamp petitions.
- Guardianships that are implemented without plans for maintaining or building the person's skills or role in running his or her own life.

A primary goal of this paper is to encourage individuals, families, friends, teachers, and human service professionals to plan for how decision-making support can best be provided, and how decision-making skills can best be developed, **before** deciding whether guardianship is needed, going to a lawyer, or going to a physician or psychologist for a formal evaluation of competence. A shared vision of how decision-making support can play a positive role in each person's life can make a major difference in how guardianship is used in our society:

- Professional evaluators will provide relevant, individualized assessments when they are challenged to do so by people who know and care about the person, and when they have easy access to information from the person's real life about the kind of decision-making support the person needs in each of the various aspects of decision-making, and how that support is or will be provided.

- Lawyers and courts will draft and order guardianships that are tailored to provide only the decision-making support the person needs, while preserving as much as possible the person's influence over his or her own life, when that is what individuals and families ask for, a plan for decision-making support already exists, and evidence from the person's life supports the plan.

Much has been written about the need to reform the laws, again with primary focus on professional evaluation and court process. Laws that provide for guardianships tailored to individual needs are important. However, there is strong evidence from other states that reforming the statutes, at least by itself, does not result in a significant increase in individualized guardianships.⁵ This may be because new laws can do no more than create a framework for guardianships designed to promote maximum dignity and independence: the person and those who know the person well must work together to create a picture of how decision-making support can be designed to help the person have the kind of life he or she wants to live. Without this picture, there is nothing to hang in the frame.

There is no question that Wisconsin's laws could be improved to promote more individualized guardianships and to ensure that the voice of people under guardianship continues to be heard.⁶ There is no question that a greater commitment of public resources is needed to recruit and support people to act as responsible guardians. On the other hand, Wisconsin already has laws that at least allow for highly individualized guardianships.⁷ The question, before and after the laws are changed, is what people with disabilities, families, teachers, case managers and others can do to make the laws work for people.

3) Think and talk about decision-making support in the transition process, and in development of individual education plans and family support plans.

The process of planning the transition from school to adult life, which begins by law at age 16 and may extend through age 21, presents a unique opportunity to focus on decision-making and the role that support in decision-making can play in the person's life, either positive or negative:

- Typically, when the process begins the person does not yet have a guardian, and people have not yet formed a fixed idea of what decision-making support would benefit the person, or of how it should be provided.
- The primary issues in thinking about decision-making support are: how does this person take in information, and use that information to make decisions, and how does that affect his or her life and future. These are issues the person's teachers

⁵ Morris Fred, *Illinois Guardianship Reform Project: Final Report*, Chicago: Equip for Equality (2001), p. 19.

⁶ See *Guardianship Reform Proposal*, Elder Law Section, State Bar of Wisconsin (1999).

⁷ See Roy Froemming and Betsy Abramson, *Guardianship of Adults: A Decision-Making Guide*, Madison, WI: Wisconsin Department of Health and Family Services (1997).

are uniquely qualified to address. First, they have the benefit of years of practical experience and analysis of how this person learns and uses information. Second, they are in a position to design and implement learning strategies that will help the person develop communication and decision-making skills needed to live the kind of life they want.

- Families have experience of how decision-making affects the person's everyday life, and are in the best position (other than the person himself or herself) to help develop a vision of what the person wants his or her life to be like. The transition process offers the opportunity for the person and his or her family to think together about how the person could be learning communication and decision-making skills at home and in the community.
- A vision of the person's future role in making decisions about his or her life can avoid plans that lock in forms of substitute decision-making that will stifle rather than promote greater dignity and independence.
- The transition process itself involves a series of decisions, and an opportunity for the person to practice decision-making in a safe and supported way. At age 18, students become legally responsible for making decisions about their educational plan. It is ironic that one reason school staff recommend guardianship is to avoid the extra work and risk involved in supporting the person to take that role.
- Particularly in the years between ages 18 and 21, education is not tied to a particular curriculum or a particular place.

If guardianship is being considered for the person, it will be helpful for everyone involved to have some basic information about the nature of different kinds of guardianships, alternatives to guardianships, the powers and responsibilities of guardians, and the process of appointing a guardian. This paper does not try to provide that kind of information, which can be found in existing publications, such as:

- Roy Froemming and Betsy Abramson, *Guardianship of Adults: A Decision-Making Guide for Family Members, Friends and Advocates*, Madison, WI: Wisconsin Department of Health and Family Services. To obtain copies without charge, specify publication number PSL 460 and send requests to:
Bureau of Aging and Long Term Care Resources
1 W. Wilson St., Rm. 450
P.O. Box 7851
Madison, WI 53707-7851
- *Understanding Guardianships: A Handbook for Guardians*, Madison, WI: State Bar of Wisconsin (1997).
- *Roles and Responsibilities of a Wisconsin Guardian of the Person* and *Roles and Responsibilities of a Wisconsin Guardian of the Person*, Madison, WI: Guardianship Support Center, Coalition of Wisconsin Aging Groups.

4) Recognize the tendency to err on the side of overuse of power to make decisions for others, and the costs of over-protection.

There is a powerful tendency on the part of the courts, the service system, and guardians themselves, to overuse the power to make decisions for other people. Understanding the reasons for this bias toward over-protection, and its costs, can also help to guard against it.

Guardianship, and other forms of substitute decision-making, tend to be overused because:

- People think full guardianship is easier and more convenient. From a court's perspective, a full guardianship means that all issues have been taken care of, and there is less risk that the court's time will be taken up if it is found that the person needs protection in an area not covered in its order. From the service system's perspective, it means that the system can look to the guardian for all decisions.
- It is more complicated and time-consuming to help a person with a cognitive disability understand and make a decision for him or herself, than it is to simply have someone else make the decision for the person.
- Courts, service systems, and guardians do not like risks. If risks are taken, and things go wrong, this is likely to create more work in planning what to do next. People who are seen as responsible for the person are more likely to be blamed when a risk is taken and something "bad" happens, than when the person is denied any right to take risks. Fears for the person's safety are often based on real-life experience. However, family members and others involved in the person's life often overestimate the security that guardianship can provide, and fail to look to other forms of support that may provide better protection of both safety and rights.

To balance this tendency, it is essential to keep in mind the costs of the overuse of power to make decisions for another person:

- Loss of decision-making power reduces the persons' opportunity to learn to make choices, and thus to develop or keep decision-making skills. We all learn by making mistakes. If a person is denied the right to take risks, he or she is also denied the opportunity to learn and grow. We all take risks in the hope of gaining something we value, and we all at times get hurt in the process. If a person is denied the right to take risks, the person will never have the opportunity to pursue aspirations that are not "sure things"—or to experience the joy of reaching goals others thought were unrealistic.
- A person who has been taught to rely on and accept the decisions of others, and who is unaware of his or her basic rights and of how to assert them, is a perfect subject for abuse and exploitation by others. If we want the person to be able to

say “no” to others, we must accept the inconvenient fact that he or she will sometimes say “no” to us.

- If someone else has power, the system and support circle are no longer challenged to always look to the person as the decision-maker, and to find imaginative ways to support him or her to understand choices and indicate preferences.
 - People can “learn” incapacity. A person who must seek the consent of another person for activities that other people perform themselves loses dignity, respect and self-confidence. People are likely to see the person as less capable than he or she actually is, and he or she is likely to live down to their expectations.
 - There is a connection between control over our lives and basic mental and physical health. There is a connection between lack of control over decisions that affect us and increased stress, disorientation, and depression.⁸ How do any of us feel, when our opinion about something important to us is not sought, or is asked for but then given no weight?
 - Substitute decision-making in an area where it is not needed creates extra work for the decision-maker, who will feel responsible for any area where he or she has been given authority, and creates fertile ground for unnecessary conflict.
- 5) **Recognize the valid purposes of decision-making support, and recognize guardianship as only one of many ways to provide decision-making support.**

There are legitimate reasons why a person may need or want decision-making support.

- The person may lack experience on which to base a choice. All young adults lack experience; those with cognitive disabilities may have led particularly sheltered lives. If that is the need, the person may need support in trying out different options and learning from those experiences.
- The person may need time and special support to understand the nature, risks and benefits of certain choices. Depending on the person’s learning style, this may mean explaining things in a way the person is most likely to understand, or providing learning through repeated observation or direct experience.
- The person may not be able to directly state his or her preferences in words. There is a powerful link between decision-making and communication. Having a communication system is a central part of being able to exercise control over one’s own life. At the same time, a person is only likely to value and use a communication system if someone actually gives weight to the things the person

⁸ Rein. *Supra*, note 7, at 1835.

says. For some people, the burden is on us to learn their preferences by making educated guesses, providing experiences and observing their reactions.

- Some people are genuinely unable to understand or assert their legal, civil and human rights, and are at risk of being exploited or dominated by other people or by agencies and institutions. The risk is particularly great for people where a person, group or institution is in a position to intimidate or isolate the person. An advocate committed to the person can be an essential bulwark against abuse, neglect and exploitation, and an essential support for the person to have access to a real life. Often, that advocacy is only possible with the legal access to information and the power to act for the person that guardianship confers.
- Access to needed services may depend on informed consent. For example, a surgeon may refuse to perform elective surgery without informed consent, or a landlord may refuse to rent an apartment unless the person signing the lease understands it. Again, in some cases this will require the legal authority of a guardian.
- Some people, even with the best support, will make decisions that place their health and safety at unacceptable levels of risk. Where that is a result of mental disability that makes the person unable to understand the risk or to take the risk into account in making decisions, and other forms of support are not effective, a guardian may necessary to protect the person from serious harm.

6) Recognize that guardianship is not an extension of parenthood: it is an exercise of governmental power, subject to constitutional limitations.

While all choices that affect our lives are important, Americans have singled out some choices as central to our idea of liberty, and given special protection to the right to make those choices without government interference. These include:

- The right to choose and exercise our own religion.
- The right to say and write what we want.
- The right to associate with people and groups of our own choice.
- The right to move around our communities, and to travel to other places.
- The right to privacy and to control of our own bodies, including the choice of whether to use birth control, be sterilized or have an abortion, and the right to conceive and raise our own children.

These rights are not absolute. The government can restrict them if it has a compelling interest in doing so, such as preventing a clear threat to the health and safety of

the person or of other people. (Freedom of speech does not include the right to yell "Fire!" in a crowded theater when there is no fire.)

It is essential for potential guardians to understand that guardianship is not simply a continuation of or substitute for parenthood past the age of 18. A guardianship is created by a court acting under state laws, and a guardian has only the powers contained in the court order, and not others. A guardian has no more power than the state would have to interfere with the person's exercise of a constitutional right.

This understanding provides a way of analyzing whether a guardian has (or potential guardian will have) authority to interfere with exercise of a constitutional right. There are two factors that go into this analysis, and that must be balanced against each other:

- First: Is the person actually exercising a right? That is, is there a way to find out what he or she prefers, and, if so, does he or she understand enough about the nature of the right to make a real choice? This is not just a yes-or-no question: people will fall on the full range from fully informed choice to no apparent preference.
- Second: If the person is making a choice, is there a compelling health or safety reason for interfering with the choice? This is a mix of how serious the harm will be, how likely it is that the harm will occur, and whether there are other ways to reduce the level of danger. The clearer it is that the person understands the nature of the choice and has a strongly held opinion, the greater the right to make that choice should be respected, and the clearer the threat to health and safety must be to overcome that right.

7) Teach the basic concepts of self-determination and self-advocacy: people have a central role to play in deciding what their lives should be like, and in planning and working to meet their goals.

One of the dangers of considering decision-making support in the transition process is that many high school students, as minors, do not have legal control of many decisions affecting their lives. Even after age 18, students often still live in the family home, and may not have had much opportunity to think of themselves as having control over their lives, or to actually exercise that kind of control. Parents often continue to make decisions about medical issues, education plans, and social activities. People with the most severe disabilities may be seen as incapable of any kind of communication or expression of preference.⁹

⁹ I have had personal experience of three cases in which physicians or psychologists had concluded that the person was not capable of expressing meaningful choices, but teachers were able to demonstrate from ongoing personal experience that the person did make and communicate choices. In one of the cases, the teacher helped the person develop a vocabulary of over 50 symbols, which he used assertively to direct his daytime activities.

Schools can make an important difference by developing or adapting curricula to teach self-determination as a skill. The basic goal should be to teach people that they can reach their own conclusions about things that affect their lives, and that they can make a difference by making plans, and taking action, to achieve personal goals.

One example of a curriculum is *Taking Part and Taking Power: The Journey to Self-Determination*,¹⁰ developed by Access to Independence, an independent living center located in Madison. As part of its Guardianship Project, the Dane County Human Services Department is working with other community groups and individuals and the schools to adapt the curriculum for use in the schools. The curriculum is in four parts, each presenting concepts in words and pictures and providing practical planning tools:

- **Decisions and decision-making.** This part covers basic concepts of having control over one's own life, making choices, and taking responsibility for choices. Students are asked to assess a wide range of decision areas, in terms of whether they make choices in those areas, whether they want to make changes, and which changes have highest priority.
- **Getting what you want.** Students are led through a process of making a plan to reach one or more of their goals, of breaking the plan down into concrete steps, and of stopping to reassess their plan as they go along. (It is important at this stage to help students consider possible negative side effects of pushing for change in their lives. For example, all of us need to weigh the impact on personal and family relationships when we decide how hard to fight for a personal goal.)
- **Finding people to help you get what you need.** This part helps the student identify people likely to listen to and respect him or her, and tips on how to get people to help in achieving a goal.
- **Preparing for the future.** The final section reviews the concepts of self-determination, and focuses on issues of control over planning and funding of community services. (This part is somewhat specific to Dane County and would need adaptation to other county systems.)

For adults, the curriculum has been taught in four weekly two-hour sessions. Adaptation to a school setting could allow for a different schedule and for ongoing follow-up as people implement their plans. Access makes a practice of asking people to take the course with someone else committed to supporting them in taking greater control of their lives. This is important in providing a connection between the course and the person's real life, but may be more challenging in a school setting.

It will be important to work with parents so that they understand the nature and purpose of the course. In some cases, self-advocacy by students may be directed at the parents, who will hopefully come to see this as an achievement rather than a problem.

¹⁰ The curriculum was written by Lisa Mills and Kirsten Bonde. For more information contact Access to Independence, 2345 Atwood Ave., Madison, WI 53704. Tel. (608) 242-8484.

This could be part of transition planning with the schools. Dane County is considering reinstituting a series of sessions on transitions issues for parents to be held outside of school and work hours, which would include a focus on self-determination issues.

8) Develop an individualized plan for development of decision-making skills and provision of decision-making support as part of a person-centered planning process.

Planning for support in decision-making should be treated as a central aspect of the person's life, to be planned for by the person and those who know the person best, in light of the person's own goals. Control over decisions affecting the person's life is a legitimate personal goal in itself. As the basic principles of this country illustrate, people value control over their own lives, apart from other outcomes. In addition, control over decision-making can be seen as a functional skill to assist in achieving personal goals. Because of its importance in helping the person's voice to be heard, or in determining who will speak for the person and on what basis, where support for decision-making is an issue it should arguably be the first issue discussed.

Family Support programs in Dane and Winnebago Counties have worked with families to discuss decision-making support as part of a process of person-centered planning. Their experience has been that this can make a significant difference in individualizing support.¹¹ A problem is finding the resources to facilitate this process. People responsible for coordinating school services are often not familiar with person-centered planning processes for other types of supports. Currently, many high-school-age students do not have anyone outside the school system in the role of service coordinator, unless they are part of a Family Support Program. Their expectation from the adult human service system is to spend time, sometimes years, on a waiting list for services. This lack of services increases the need for individualized planning to use the resources that do exist; it should not be used as a reason to postpone person-centered planning, as if the person's adult life will begin only when he or she comes off the waiting list.

9) Identify decisions that may need to be made, and the kinds of support that may help.

If it is accepted that decision-making will be discussed as both an area to set personal goals and an area to develop functional skills, the next thing to do is to identify the questions to ask in deciding whether education or support is needed and in arriving at an appropriate plan for education and support. Adding to the complexity of the process, the person's desire for personal control, and the level and type of support needed, will vary depending on the particular area of decision-making. For example, a person may have little skill or interest in making decisions on medical treatment, and at the same time have strong interest and skills in making decisions about personal relationships.

¹¹ Interviews with Heidi Rossiter, Family Support and Resource Center of Dane County, and Beth Biesinger, Winnebago Human Services Department.

Before petitioning for guardianship, the person, family and other people who know the person well should identify the areas in which they believe the person may need support, either in making decisions or in asserting or defending personal rights. Then, for each of these areas, they should try to answer these questions:¹²

- **Decision-making capacity.** Is the person able to understand significant information on the nature, risks and benefits of the various options, or on the nature and significance of his or her rights, if explained in a form the person is most likely to understand? Is the person able to use that information in making decisions that affect his or her life?
- **Level of risk.** If the person has a significant lack of decision-making capacity, what level of risk to health, safety, rights, possessions and access to a desired life results from his or her inability to make informed decisions or understand and assert rights?
- **Training and experience.** Has the person had the opportunity to develop decision-making capacity through training and practice? Has the person had needed evaluation and support to develop a functional means of communication? Has the person had a base of experience needed to make decisions or understand his or her rights? If not, would skill-building or greater experience be likely to help develop, maintain or restore decision-making ability?
- **Informal support.** Does the person have a strong informal network of support committed to identifying and realizing his or her preferences, hopes and dreams? If so, is the person able and willing to work with this network of support in a way that will allow decisions to be made on a cooperative basis that will meet the goals of the life plan without use of guardianship? (This may include the use of alternatives such as dual-signature checking, power of attorney, etc.) If informal support is an option, is it likely to be more or less respectful of the person's voice than a guardian would be?
- **Guardianship as a solution.** If education, experience and informal supports will not reduce the risk of harm in a particular area to an acceptable level, is guardianship likely to help reduce the risk? Do the benefits of guardianship outweigh the costs? (Guardianship is primarily the power to give consent on the person's behalf, not the power to coerce the person into doing things. Where the person understands the nature of a decision or right and has a strong desire to be in control of decisions, guardianship is not only less appropriate, it is also less likely to be effective in reducing the risk of harm and to have higher costs.)

¹² For other valuable approaches to evaluating need for decision-making support, see Ontario Office of the Public Guardian and Trustee, *Guidelines for Conducting Assessments of Capacity* (1996) and J. Wilen Berg et al., "Constructing Competence: Formulating Standards of Legal Competence to Make Medical Decisions," 48 *Rutgers Law Review* 345 (1996).

- **Limiting guardianship.** If guardianship is appropriate, how can it be limited to only those decisions and rights where the risks justify the use of guardianship?
- 10) **Include teaching of communication and decision-making skills in the Individual Education Plan, to be taught in the context of meaningful, real-life decisions.**

As discussed above, schools have a role in helping people learn to make and communicate decisions. The transition years provide a unique opportunity for providing individualized community-based experiences and real-life opportunities for supported decision-making. A person-centered planning process provides a way of identifying both the priority areas in which the person needs decision-making support, and the ways in which expanded experience, practice of decision-making skills, and development of communication methods and skills can promote self-determination.

One obvious but often neglected opportunity to teach the person skills in decision-making is the IEP process itself. Under the law, students over age 18 who do not have guardians have the authority to make IEP decisions formerly held by the parents. Often, the law requiring schools to inform parents and students of this authority is not followed, or students are encouraged to continue to delegate it to parents. Taking the student's role seriously will require everyone to take decision-making support more seriously.

- 11) **If guardianship is being considered, make a plan for how this particular guardian will carry out his or her responsibilities for this particular person, in line with guiding principles that reflect community expectations.**

Guardianship is not, or should not be, the same for each person. If it is going to be helpful for the particular person's needs, it is important to ask how that help will actually be delivered. Thinking this through can also be helpful to answering some of the questions posed in the last section, in particular the question about whether guardianship, in actual practice, will help solve the perceived problem and do more good than harm. It is also an opportunity to plan for the person's ongoing participation and skill development in making decisions and exercising rights legally transferred to the guardian.

It can be helpful to have a set of general principles that set out community expectations about the role of guardians in providing decision-making support, and the continuing role of individuals under guardianship in influencing decisions that affect their lives. Setting clear expectations at the outset, and having principles to which to refer, can:

- Help people involved in planning support for a person decide if guardianship is a useful tool for the particular person.
- Help potential guardians see guardianship as a positive support, to understand their responsibilities, and to decide if guardianship is an appropriate role for them.

- Provide an ongoing set of guidelines where there are difficult decisions to make, or where there are disagreements among the people involved in the person's life over how guardianship should be exercised.

In 2000, the Sauk County Human Services Department brought together a group of people, including people with disabilities, guardians, human service professionals, and people who work in and with the courts to develop a draft set of guiding principles that embodies many of the values that underlie this paper. It is included as an attachment to this paper, not as something for other communities to adopt as written, but as a place from which to start a discussion. The process is as important as the list itself. Bringing people from the community together to discuss what the principles should contain produces a list that reflects community values and has legitimacy in that community, and starts a discussion among people involved in guardianship that can go on to identify and reduce barriers to carrying out the guardianship principles.

Guiding Principles Related to Guardianship and Guardian Roles for Persons with Developmental Disabilities

All individuals have the same basic rights, including rights to safety, freedom of speech, freedom of association, privacy rights, and freedom of mobility. A guardian may decide to restrict these rights only when there is a compelling health or safety reason for doing so. In making such a decision, the guardian must take into account the person's ability to understand the choices involved and the level of risk of each choice. The greater the person's understanding of the consequence of a choice, the less the guardian should interfere with that choice. A guardian's decision to restrict a person's rights indicates a need for the system to assure that supports to the person are being provided in the least restrictive manner, and that the person's rights, as well as health and safety, are assured.

The individual has a right to meet and talk with others. This includes but is not limited to the right of a person under guardianship to meet and talk with a case manager, an advocate, or other support persons without the presence of a guardian.

Decision-making is both a human right and a functional skill. Some people have a functional need for support in decision-making, due to age, inexperience, or cognitive disability, in order to protect health, safety or rights. Guardianship is one of several responses that could address that need. The potential need for guardianship should be assessed as part of a person-centered planning process. If guardianship is recommended, it should be planned in a manner that retains as much control and dignity for the person as possible, builds his or her decision-making skills, and continues to involve the person in decisions that affect his or her life.

Guardianship requires active effort to learn and respect the preferences of the person. A significant part of a guardian's role is to learn and respect the person's preferences, and promote the person's rights as a citizen. This responsibility requires finding ways for the person to indicate choices and preferences, and finding ways to respect those preferences consistent with the person's overall best interests. Ultimately, a guardian must make decisions based upon the best interest of the person. Often those interests are best understood within the context of the person's relationship to others who know and care about them and within the context of the community in which the person lives. Important preferences include those related to identifying members to be part of a person's support circle and to any needed or desired planning processes.

A guardian of the person has a right and duty to be a partner in services planning and to ensure that the person's best interests are served. Guardians have the right to have access to records and service planners, and the power to give or withhold informed consent in the areas of their designated authority. A guardian is expected to make a commitment to know the person well in order to actively participate in decision-making on behalf of the person. As a general rule, the guardian should regularly spend time with the person, not less than quarterly. In turn, the service system should value and respect the guardian's commitment, knowledge, personal bond and continuity over time with the person they are supporting.

