



# CHAPTER 1: DECISION-MAKING BY PEOPLE WITH INTELLECTUAL DISABILITIES: THE IMPORTANCE OF SELF- DETERMINATION

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This publication is supported by a grant from  
the Pennsylvania Developmental Disabilities Council.

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Until relatively recently, individuals with intellectual disabilities in this country usually lived their entire lives in institutions, segregated from their peers, families, and society as a whole. There were few, if any, issues concerning consent and decision-making in institutions. It was generally presumed that institutionalized individuals were unable to make decisions regarding their own lives due to their disabilities. Beyond this patronizing assumption, the very nature of institutional care undermined individuals' decision-making abilities. Prolonged, pervasive denials of the opportunity to make even basic decisions simply exacerbated the institutionalized persons' dependence on others to make decisions for them.

In the past 40 years, however, the model of care for people with intellectual disabilities has substantially evolved, thanks to the concerted efforts of self-advocates, families, lay advocates, and concerned professionals. Today, most individuals with intellectual disabilities live in their own homes in integrated communities. As integration has become the norm, there has been increased focus on the ability of individuals to participate in community life to the fullest extent possible.

As for all human beings, community life for people with intellectual and other developmental disabilities involves daily decision-making. Many of these decisions are quite basic. What should I eat? Should I go to the store? What should I wear? Other decisions, though, can have important and long-lasting consequences. Where should I live? Should I get treatment for an illness? Should I get married?

The freedom to make decisions -- even decisions that might have adverse consequences -- is fundamental to personal autonomy and self-determination. This right, however, is not unlimited. In some situations, substitute decision-makers may be necessary and appropriate. Yet, in determining what role, if any, substitute decision-making should play in the life of an individual with an intellectual disability, there are several considerations to bear in mind.

## **I. DISABILITY VARIATION**

The presence of a developmental disability, including an intellectual disability, by itself does not tell us anything about a particular individual's decision-making capacity. Decision-making abilities are not the same for all people with developmental disabilities. People with developmental disabilities are individuals whose abilities and disabilities are subject to wide variation. Obviously, individuals with physical disabilities who have no cognitive limitations will rarely, if ever, need a substitute decision-maker.

Many individuals with autism or an intellectual disability have expressive and receptive language abilities to communicate many of their needs and desires and have sufficient comprehension and reasoning skills to understand their choices. Some individuals with autism or an intellectual disability might not have strong expressive language skills, but can still communicate their desires through a variety of means and understand their choices.

There are, however, other individuals with cognitive disabilities whose decision-making abilities are compromised, at least to some extent, and they may need some form of assistance, guidance and education, or perhaps a substitute decision-maker. Adolescents and young adults with severe emotional disorders might be able to make decisions some of the time, but not other times. In short, the ability to make decisions must be determined on an individual basis, and based on the situation and circumstances, without resort to assumptions and stereotypes.

## **II. VARIATION IN TYPES OF DECISIONS**

There are wide varieties of decisions that affect the lives of individuals with disabilities, including everyday living decisions; decisions about disability-related services and supports (housing, day programs, therapies); decisions about medical and mental health care; decisions about finances; and decisions about marriage, sexuality, and procreation. The fact that an individual is unable to make some decisions does not mean that she is unable to make any decisions. The type of decision that is at issue can be as important as the type and extent of an individual's disability in determining whether a substitute decision-maker is necessary, appropriate, or lawful.

## **III. DECISION-MAKING EXPERIENCE AND TRAINING**

One of the key deterrents to people with intellectual disabilities making decisions is the extent to which they have been previously denied the choice to make important decisions. Even outside the institutional context,

people who are "integrated" have too often been the subject of decisions rather than an active participant in them. This is changing as we recognize the importance of people having as much control as possible over their own lives. It is important to provide decision-making training to individuals with disabilities as well as opportunities to make decisions that affect their lives to the maximum extent possible.

#### **IV. NATURAL SUPPORT SYSTEMS**

Substitute decision-making is often thought to be necessary to protect individuals from making decisions that are harmful to their health and well-being. Although there are many types of formal substitute decision-making (such as powers of attorney and guardianship), it is important to bear in mind that such formal arrangements are often unnecessary if the individual has an adequate natural support system. A circle of family members, friends, or lay advocates can work with the individual to assist him to make decisions.

In sum, decision-making is part of daily life and a key element of self determination and community integration. People with intellectual disabilities should be encouraged to make decisions and choices that affect their lives, whether major or minor, to the maximum extent that they can do so. Substitute decision-making should be the option of last resort and should be narrowly tailored to assure that individuals with intellectual disabilities are not stripped of their right to make choices when they can do so.

## Contact Information

If you need more information or need help, please contact Disability Rights Pennsylvania (DRP) at 800-692-7443 (voice) or 877-375-7139 (TDD). The email address is: [intake@disabilityrightspa.org](mailto:intake@disabilityrightspa.org).

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