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PART I

Overview

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Introduction to Supported Decision-Making and Its Emergence in the Disability Field

Supported decision-making is receiving attention throughout the world as a means to enable people with disabilities to remain at the center of decision-making processes in their lives. This text is focused on the emergence of theoretical and empirical frameworks that operationalize the provision of supports for decision-making to enable people with disabilities to be agentic and involved in decisions about their lives. This introductory chapter provides a context for the emergence of supported decision-making, the relationship between guardianship and supported decision-making, and a frame for understanding the remaining sections and chapters of the text.

"Justice for Jenny," Section 1

The year she turned age twenty-nine, Margaret "Jenny" Hatch had a job she loved, lived in her own apartment, had friends she enjoyed being with, and was active in her church and politics (Hatch, Crane, & Martinis, 2015). Perhaps most importantly for Jenny, who has Down syndrome, she had people in her life she could count on, who helped her when she needed it. Jenny's friends, employers, professionals that she knew, and others, helped her when she needed information to make decisions. With their support, and her natural capabilities, Jenny had a life like almost everyone else: she worked, lived interdependently, and took care of herself; she made her own choices on where to go, who to see, and what to do.

Unfortunately for Jenny, she was struck by a car while riding her bicycle. Shortly thereafter, she was served with a petition for full guardianship, which asked the local state court to appoint another person to take control over Jenny's life, and to make all decisions for her. After a short hearing on the petition, the court placed Jenny under a temporary guardianship. Jenny's guardian was given the legal power to decide, at least for the time being, where she lived, who she saw, how she spent her time and money, what (if any) health care she received, and what type of education, living, and employment services she was provided (*Ross and Ross* v. *Hatch*, 2013).

Guardianship

While guardianship laws vary from state to state, in general, Americans are ordered under guardianship when a state court decides that they cannot direct their lives or make some or all decisions due to having a disability or condition that limits their ability to do so. In essence, the individual under guardianship is determined to be incapacitated in the eyes of the law. In these circumstances, the local state court, often called a probate court, then appoints a third party, usually called a *guardian* but in some states a *conservator*, to direct the person's life and make decisions for the person in areas where the court feels he or she cannot (Quality Trust for Individuals with Disabilities, 2013). In cases in which the court directs that all life decisions are to be determined by the guardian an order of *plenary* guardianship is made, and where only some decisions are covered this is called *limited* guardianship.

The surrogate decision-making process has been roughly the same for more than 2,000 years. In ancient Rome, for example, people deemed *feeble-minded* were placed under the control of *curators* (Fleming & Robinson, 1993). In feudal England, the 1324 statute *De praerogativa regis* stated that people considered to be *idiots* and *lunatics* (O'Sullivan, 2002) would be placed under *committees* that would have the power to make decisions in their place (Regan, 1972). The United States followed this model, giving states "all the powers in this regard which the sovereign

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possesses in England" (*Late Corp. of the Church of Jesus Christ of the Latter Day Saints* v. *United States,* 1890, p. 57).

Throughout history, society has viewed the guardianship process as "a humanitarian response to the vulnerability of the incompetent" (Frolik, 1998, p. 350). This paternalistic view has contributed to the estimated number of Americans under guardianship tripling since 1995, with most under plenary guardianship (Reynolds, 2002; Schmidt, 1995; Uekert & Van Duizend, 2011). Yet this dramatic rise in guardianship orders has not typically been accompanied by systematic and individualized analyses as to whether and when these individuals actually require guardianship or, once guardianship is ordered, "whether the protected person continue[s] to need or benefit" from it (Wright, 2004, p. 60).

"Justice for Jenny," Section 2

While under temporary guardianship, Jenny Hatch found herself in a position where, regardless of what she wanted, had done before, or had shown the ability to do, someone else controlled her life decisions. In Jenny's words:

> I was forced to live in a group home. I did not like it there. I didn't feel safe there. I would tell everyone, but no one would listen. They took away everything that was important to me. I was not allowed to work at my job or see my friends. They would not even let me go to my church. My computer and my cell phone were taken away and I was not allowed to even call my friends … They told me

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> I had to work at [a segregated "sheltered" workshop]. I snapped snaps together all day and it was boring. I did not like it. I wanted my life back, but they told me to forget about my old life and move with my new life. (Hatch, Crane, & Martinis, 2015, p. 66)

Jenny's *full* or *plenary* guardianship is by far the most common ordered by a court (Frolik, 2002). One study found that, in more than 90 percent of the guardianships reviewed, the guardian had authority to make *all* life decisions for the ward (Teaster et al., 2007). Another found that 87 percent of the guardianships it reviewed across ten states gave the guardian full authority over the person (Lisi, Burns, & Lussenden, 1994). In the words of one leading commenter, "It seems that as long as the law permits plenary guardianship, courts will prefer to use it" (Frolik, 1998, p. 354).

Overbroad and Undue Guardianship

The recent three-fold increase in guardianship, when coupled with the historical view of guardianship as benevolent, raises concerns about the overuse of *overbroad and undue* guardianships (Blanck & Martinis, 2015). Guardianships are overbroad or undue when they are imposed on people who are able to make their own decisions and direct their own lives, either on their own or through the use of an alternative to guardianship, or when they restrict more of the person's rights than necessary (Martinis, 2015a). Scholars and researchers have contended that these types of undue guardianship cause

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a “significant negative impact on … physical and mental health, longevity, ability to function, and reports of subjective well-being” (Wright, 2010, p. 354). As Congressman Claude Pepper, Chair of the US House of Representatives Select Committee on Aging, stated:

> The typical ward has fewer rights than the typical convicted felon … By appointing a guardian, the court entrusts to someone else the power to choose where they will live, what medical treatment they will get and, in rare cases, when they will die. It is, in one short sentence, the most punitive civil penalty that can be levied against an American citizen, with the exception, of course, of the death penalty. (House of Representatives, 1987, p. 4)

Overbroad and undue guardianship may cause such harm because it decreases *self-determination*. Self-determination refers to making or causing things to happen in one’s own life, and “enhances the possibilities for people to exert some authority in their lives” (Wehmeyer & Schwartz, 1998, p. 4). People exercise self-determination by making the choices that set their life course, the simple and complex everyday decisions (Shogren et al., 2015a) that result in them becoming “causal agents … actors in their lives instead of being acted upon” (Wehmeyer et al., 2000, p. 440). When a person is court ordered into a plenary guardianship, their self-determination necessarily decreases because someone else is given the power to make decisions for them, *instead* of them (Blanck & Martinis, 2015).

Numerous studies find that, when people exercise more self-determination, they have a demonstrably better quality of life. Research by Shogren, Wehmeyer, Palmer, Rifenbark, and Little (2015b) and Powers and colleagues (2012) found that young adults with disabilities who were more self-determined were more likely to be employed, independent, and live in their communities. McDougall, Evans, and Baldwin (2010) found a positive association between self-determination and perceived quality of life in people with disabilities.

These studies follow in the wake of others. Wehmeyer and Schwartz (1997) found that young adults with cognitive impairments who had higher self-determination were more likely to live independently, manage their money, and be employed. Wehmeyer and Palmer (2003) likewise found that adults with disabilities who exercised greater self-determination were more likely to live independently, have greater financial independence, be employed at higher paying jobs, and make greater advances in their employment. Recent federal laws, such as the Achieving a Better Life Experience (ABLE) Act of 2014, create tax-advantaged savings accounts for people with disabilities to further financial independence by allowing that certain living expenses related to education, housing, and transportation may be covered with such savings (Morris, Rodriguez, & Blanck, 2016).

Other studies find that women with intellectual disability who are enabled to be more self-determined are better able to recognize potentially abusive situations and avoid abuse (Khemka, Hickson, & Reynolds, 2005). Moreover, older adults who are more self-determined are better able to adjust to their increasing care needs (O’Connor & Vallerand, 1994).

Overbroad and undue guardianship limits individual self-determination because it takes life control away from people who otherwise have the ability to make their own decisions and direct their own lives (Blanck & Martinis, 2015). Decades of research has found that people who are denied opportunities for self-determination often “feel helpless, hopeless, and self-critical” (Deci, 1975, p. 208) and experience “low self-esteem, passivity, and feelings of inadequacy and incompetency” (Winick, 1995, p. 21), decreasing their ability to function. Accordingly, overbroad or undue guardianship “not only divests the individual of the important right to self-determination but also marginalizes that person and removes him or her from a host of interactions involved in decision-making” (Salzman, 2010, p. 160).

The personal and social isolation inherent in overbroad and undue guardianship has led legal commentators to argue that it violates the “integration mandate” of the Americans with Disabilities Act (ADA) of 1990 and as amended in the ADA Amendments Act in 2008 and 2012 (Hatch, Crane, & Martinis, 2015; Salzman, 2010). Title II of the ADA states that public entities – governments and any “instrumentality of a state or local government” (ADA, 2012; 42 U.S.C. § 12131) – must ensure that “no qualified individual with a disability shall, by reason of such disability, be excluded from participation in or be denied the benefits of the services, programs, or activities of a public entity, or be subject to discrimination by any such entity" (ADA, 2012; 42 U.S.C. § 12132). The regulations of the ADA state that public entities must "administer [their] services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities" (ADA, 2008; 28 C.F.R. § 35.130[d]). The "most integrated setting" is one "that enables individuals with disabilities to interact with nondisabled persons to the fullest extent possible" (ADA, 2008; 28 C.F.R. Pt. 35, App. A 2010 addressing 28 C.F.R. § 35.130).

In the seminal United States Supreme Court case *Olmstead* v. *L.C.* (1999), two women with intellectual disability argued that the State of Georgia had violated the ADA's integration mandate when it determined to house them in segregated institutions rather than in integrated community settings. The Supreme Court agreed stating, "[u]njustified institutional isolation . . . is a form of discrimination" (527 U.S. 581 at 600).

Salzman (2010) and Hatch, Crane, and Martinis (2015) argue that people in overbroad or undue guardianships suffer the same isolation, in violation of the ADA, as people unjustifiably institutionalized. Salzman states that people forced into overbroad or undue guardianships are "constructively isolated" from their communities because their guardians control where they live, whether they receive medical