

“The Right to Make Choices”: The National Resource Center for Supported Decision-Making

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Abstract

Research shows that self-determination and the right to make life choices are key elements for a meaningful and independent life. Yet, older adults and people with disabilities are often placed in overly broad and restrictive guardianships, denying them their right to make daily life choices about where they live and who they interact with, their finances, and their health care. Supported decision-making (SDM)—where people use trusted friends, family members, and professionals to help them understand the situations and choices they face, so they may make their own decisions—is a means for increasing self-determination by encouraging and empowering people to make decisions about their lives to the maximum extent possible. This article examines the implications of overly broad guardianship and the potential for supported decision-making to address such circumstances. It introduces the National Resource Center for Supported Decision-Making as one means to advance the use of supported decision-making and increase self-determination.

Key Words: *supported decision-making; guardianship; self-determination*

In 1987, the U.S. House of Representatives Select Committee on Aging held hearings titled *Abuses in Guardianship of the Elderly and Infirm: A National Disgrace*. Summarizing his Committee’s findings, Chairman Claude Pepper famously 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. (*Abuses in Guardianship*, 1987, p. 4)

Almost three decades later, the number of adults under guardianship has tripled (Reynolds, 2002; Schmidt, 1995; Uekert & Van Duizend, 2011).

Today, many older Americans and people with disabilities are placed in overbroad and unwarranted guardianships, losing their right to make choices regarding where to live, what to do during the day, with whom to interact, their personal finances and health care (Dinerstein, 2012). To advance and protect the right of these citizens to make core life choices and direct their lives to the maximum of their abilities, Quality Trust for Individuals with Disabilities, the Burton Blatt Institute at Syracuse University, and the Kansas University Center on Developmental Disabilities, together with a broad coalition of community partners and stakeholders, have launched the National Resource Center for Supported Decision-Making. Funded through a multi-year cooperative agreement with the U.S. Administration on Community Living, the National Resource Center aims to lead and coordinate efforts to make supported decision-making—where people use trusted friends, family members,

and professionals to help them understand the situations and choices they face, so they can make their own decisions (Dinerstein, 2012; Quality Trust for Individuals with Disabilities, Quality Trust, 2013)—a recognized and, as appropriate, preferred alternative to guardianship.

This article provides an overview of the negative effects of overly broad and unnecessarily restrictive guardianship arrangements, the potential benefits of supported decision-making as an alternative to guardianship, recent developments in research and practice in supported decision-making, and the National Resource Center's goals to increase awareness and advance the practice of supported decision-making.

Negative Effects of Overly Broad and Restrictive Guardianship

Governments have long appointed substitute decision makers for people they believe are “by reason of age or disability . . . incapable of making such decisions for themselves” (Winick, 1995, p. 27). Guardianship's roots extend as far back as the Roman Empire, where *curators* were appointed to make decisions for people with cognitive disabilities (Fleming & Robinson, 1993).

Feudal England developed the concept of *parens patriae*—that the king is “parent of the country” and responsible for protecting the property of people deemed unable to do so on their own (Payton, 1992). The 1324 statute *De Praerogativa Regis* divided people with disabilities into *idiots* and *lunatics* (O'Sullivan, 2002) and authorized the appointment of committees to make decisions for them in the king's name (Regan, 1972).

The newly formed United States adopted England's *parens patriae* model, granting to states “all the powers in this regard which the sovereign possesses in England” (*Late Corp. of the Church of Jesus Christ of the Latter Day Saints v. United States*, 1890, p. 57). Today, guardianship is still governed by state law, with each state enacting its own statutes, policies, and procedures. As a general matter, guardianship is ordered when a state court determines that a person is not able to make some or all life decisions, the person is thereby in need of *protection*, and there are no less restrictive options other than court-ordered guardianship. (*Less restrictive options* are other ways of making decisions that protect the person's rights and self-determination as well as or better than guardianship.) The court then

appoints a third party to make some or all decisions for that person, who becomes known as the “ward.” (Broadly speaking, *limited* guardianship occurs when the guardian is authorized to make some, but not all, decisions for the ward. *Full, general, or plenary* guardianship occurs when the guardian is authorized to make all decisions for the ward.)

American society, as in other countries and historically, generally conceives of guardianship as “a humanitarian response to the vulnerability of the incompetent” (Frolik, 1998, p. 350), protecting those who “cannot take care of themselves in a manner that society believes is appropriate” (Kapp, 1999, p. 109). Because guardianship has traditionally been assumed to be benevolent and protective of those “less able” to decide for themselves, many state laws and courts have not closely reviewed whether people with disabilities and older adults in fact require forms of guardianship or, once guardianship is established, “whether the protected person continue[s] to need or benefit” from it (Wright, 2004, p. 60).

With the development of the disability civil rights movement, as embodied in the Americans With Disabilities Act of 1990 (2006; Blanck, 2014a, 2014b), researchers and practitioners are finding that overly restrictive guardianship regimes may be associated with decreased life competencies and overall health. This is because guardianship may “set up expectancies of failure . . . that diminish subsequent [life] performance” (Winick, 1995, p. 15), thereby decreasing and denying individual self-determination.

Self-determination describes actions that enhance the possibilities for people to make or cause things to happen in their lives (Shogren, Wehmeyer, Palmer, Forber-Pratt, et al., in press). Individuals exercise self-determination when making simple and complex everyday life choices regarding where, how, and with whom they live. By doing so, they become “causal agents . . . actors in their lives instead of being acted upon” (Wehmeyer, Palmer, Agran, Mithaug, & Martin, 2000, p. 440). A person denied self-determination often “feel[s] helpless, hopeless, and self-critical, and will not behave because he can see no use in behaving” (Deci, 1975, p. 208).

Accordingly, people labeled *incompetent* or *incapacitated* and placed in overbroad guardianships are deprived of self-determination and the opportunity to be causal agents in their own lives. In these circumstances, people often experience “low self-esteem, passivity, and feelings of inade-

quacy and incompetency,” decreasing their ability to function (Winick, 1995, p. 21). Thus, imposing a guardianship to “protect” a person for his or her “own good” may actually be associated with the negative behaviors and symptoms that led to the guardianship proceeding in the first place.

Despite such findings, there are “deeply embedded tendencies toward protection over autonomy, and courts continue to issue guardianship orders that are not necessary and are overly broad in scope” (Salzman, 2010, p. 178). Indeed, almost thirty years after Representative Pepper described guardianship as “the most punitive civil penalty that can be levied against an American citizen” (*Abuses in Guardianship*, 1987, p. 4), the estimated number of American adults under guardianship has increased from 500,000 to 1.5 million just since 1995 (Reynolds, 2002; Schmidt, 1995; Uekert & Van Duizend, 2011).

More troubling, plenary guardianship (in which a court gives a guardian authority across all legal rights) is ordered in the vast majority of cases (Frolik, 2002). One study found that less than 10% of the public guardianships it reviewed were limited—meaning that in nine of 10 cases, the guardian had authority to make all life decisions for the ward (Teaster, Wood, Lawrence, & Schmidt, 2007). Another found that only 13% of the guardianships it reviewed across ten states were limited in scope (Lisi, Burns, & Lussenden, 1994). A third found that plenary guardians were appointed in 54% of the cases reviewed and that there was little difference between the authority given to full and limited guardians (Millar & Renzaglia, 2002). As one commenter states, “Courts do not [order limited guardianships] because there is little reason or incentive to do so. It seems that as long as the law permits plenary guardianship, courts will prefer to use it” (Frolik, 1998, p. 354). Furthermore, even as the demand for plenary guardianships increases, one “cannot say with confidence that if any one of us becomes incapacitated that a robust system is in place to protect our person and our financial assets” (Uekert, 2010, p. 6).

The present trend favoring plenary guardianship continues despite federal laws and U.S. Supreme Court decisions mandating community integration (e.g., Americans With Disabilities Act, 2006; Developmental Disabilities and Bill of Rights Act, 2006; *Ohmstead v. L.C.*, 1999; Rehabilitation Act of 1973, 2006). Consequently, there is a compelling need to develop and implement, at a minimum, the opportunity for alternatives to

guardianship that respect individual self-determination, and that encourage and empower older adults and individuals with disabilities to make their own life choices to the maximum of their abilities.

Self-Determination and Supported Decision-Making

Supported decision-making has shown promise to increase self-determination and quality of life, and to alter the prevalent view that older Americans and people with disabilities inevitably require guardianship. Although there is no “one-size-fits-all” model of supported decision-making, it generally occurs when people use one or more trusted friends, family members, professionals, or advocates to help them understand the situations and choices they face so they may make their own informed decisions (Dinerstein, 2012; Quality Trust, 2013). As such, supported decision-making mirrors how most adults make daily decisions—whether to get car repairs, sign legal documents, consent to medical procedures, review financial documents, and the like. In each instance, individuals seek advice, input, and information from knowledgeable friends, family, and professionals so they may make their own informed choices (Quality Trust, 2013).

Supported decision-making is increasingly being used in the United States and internationally (Kohn, Blumenthal, & Campbell, 2013). For instance, in the United States, Texas and Virginia have passed laws authorizing and studying the use of supported decision-making. Supported decision-making also is recognized in Article 12 of the United Nations Convention on the Rights of Persons with Disabilities (CRPD), which presumes that all people have legal capacity and that governments must take appropriate action to provide people with access to the supports they need and want to make their own life decisions (Dinerstein, 2012). Among others, the governments of Australia, Canada, Germany, Great Britain, and Ireland have implemented forms of supported decision-making systems.

By ensuring that the individual is the final decision maker on his or her own life circumstances, supported decision-making empowers people to be causal agents in their lives, increasing their self-determination (Kohn et al., 2013). As mentioned, research indicates that people who exercise greater self-determination have more positive quality of

life outcomes and improved quality of life. Recent studies find that young adults who receive instruction designed to increase self-determination enhance their employment circumstances, independence in daily life, and community integration (Powers et al., 2012; Shogren, Wehmeyer, Palmer, Rifenburg, & Little, in press).

These findings build on those from other studies showing a positive relationship between self-determination and quality of life. Wehmeyer and Schwartz (1997), for instance, found that young adults with greater self-determination were more likely to want to live independently, manage their money, and be employed. In another study, adults who exercised more 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 (Wehmeyer & Palmer, 2003). Khemka, Hickson, and Reynolds (2005) found that women with intellectual disability (ID) provided with education to improve problem solving and independent decision making were more likely to identify situations where they could be abused and less likely to suffer abuse.

Kohn et al. (2013) concluded that supported decision-making has the “potential to be an empowering alternative to the much-maligned process of guardianship The question, however, is whether supported decision-making can fulfill that promise” (p. 1157). The authors cautioned, though, that:

It is imperative that substantial further research be conducted to examine how supported decision-making actually operates Research is needed to determine the extent to which supported decision-making approaches achieve their goals, and the conditions under which they are likely to do so (Kohn et al., 2013, p. 1157).

Recent Developments in Supported Decision-Making

As noted, the call for and use of supported decision-making is increasing (for a related summary, see the Brief for Amici co-authored by Professor Blanck and Mr. Martinis in *In Re: Guardianship of the Person and Estate of Ryan Keith Tonner, an Incapacitated Person*, 2014). In 2009, the Texas legislature created a pilot program to

“promote the provision of supported decision-making services to persons with intellectual and developmental disabilities and persons with other cognitive disabilities who live in the community” (Volunteer-Supported Decision-Making Advocate Pilot Program, Tex. Gov’t Code Ann. § 531.02446, West 2009). The program called for training volunteers to provide support needed to empower people “to make life decisions such as where the person wants to live, who the person wants to live with, and where the person wants to work, without impeding the self-determination of the person” (§ 531.02446(a)(4), West 2009).

In 2012, a group of stakeholders met in New York to discuss the rights of people with ID to make their own decisions in light of the CRPD. (Participants included representatives from the American Bar Association, the United States Department of Justice, the Administration on Intellectual and Developmental Disabilities, and the National Guardianship Association.) Their goal was to explore concrete ways to move from a model of substituted decision-making, like plenary guardianship, to one focusing on alternatives like supported decision-making. The participants identified a number of important and difficult issues, including the need to:

- revise guardianship standards to stress supported, independent decision-making;
- set standards and expectations for “supporters”; and,
- prevent abuse and undue influence without denying legal capacity (Quality Trust, 2013, p. 2).

The following year, in 2013, a 29-year-old woman named Margaret “Jenny” Hatch won a landmark legal battle protecting her right to make her own life decisions using supported decision-making, instead of being subjected to a permanent, plenary guardianship (see Hatch this volume). (Professor Blanck served as an expert witness for Ms. Hatch. Mr. Martinis served as her lead counsel.)

Like many people with disabilities, Jenny faced a guardianship petition challenging her right to make decisions, including choices she had made for herself such as where to live, whether to work, how to use the Internet and a cellular telephone, and whom to see (*Ross and Ross v. Hatch*, 2013). At the request of her parents, the court placed Jenny in a temporary guardianship and placed her in a group home, where her phone and laptop were taken away and she was not allowed to go to her job and see her friends.

Fortunately, after a year of litigation and a trial before a state court judge, Jenny won her right to make her own decisions using supported decision-making and “now lives and works where she wants, has the friends she chooses, and encourages others to do the same” (Quality Trust, 2013, p. 2).

Jenny’s court victory received national and international attention for highlighting “an individual’s right to choose how to live and the government’s progress in providing the help needed to integrate even those with the most profound needs into the community” (Vargas, 2013). After the trial, Jenny and Quality Trust partnered to form the Jenny Hatch Justice Project (JHJP). In its first year, the JHJP provided representation and technical assistance in over 100 guardianship matters; co-led coalitions that advanced alternatives to guardianship by successfully advocating for changes in state laws, policies, and practices; and trained and worked with individuals and public and private entities to implement policies advancing the use of supported decision-making and other alternatives to guardianship.

Later in 2013, Quality Trust, the Burton Blatt Institute, and the Council on Quality and Leadership convened a group of 65 national and international thought leaders for an Invitational Symposium on supported decision-making. (Symposium participants included the Administration on Intellectual and Developmental Disabilities, the Autistic Self-Advocacy Network, the Bazelon Center for Mental Health Law, Collaboration to Promote Self-determination, Elizabeth Boggs Center, and Open Society, among others.) Hosted by American University Washington College of Law, the Symposium brought together stakeholders, leaders, and policymakers to discuss principles of education, research, and advocacy to guide future actions to advance supported decision-making (Quality Trust, 2013).

Symposium attendees were organized into four working groups, which reached consensus on the fundamental principles that should guide future action, including:

- compiling information and data on supported decision-making usage and disseminating it to stakeholders;
- researching how supported decision-making is working in the U.S. and abroad;
- developing and implementing best practice standards for supported decision-making; and,
- identifying barriers to guardianship reform and the actions needed to overcome them (Quality Trust, 2013, p. 11).

In early 2014, the Virginia General Assembly, based in part on the advocacy of Jenny Hatch and the JHJP, directed the state Secretary of Health and Human Services to study supported decision-making (VA H.J.R. 190, 2014). The Secretary is to review ways supported decision-making may be used in Virginia and has been implemented elsewhere to “recommend strategies to improve the use of supported decision-making in the Commonwealth and ensure that individuals with intellectual and developmental disabilities are consistently informed about and receive the opportunity to participate in their important life decisions” (VA H.J.R. 190, 2014).

In mid-2014, the Administration for Community Living in the U.S. Department of Health and Human Services made funding available for a first-of-its-kind training and technical assistance center on supported decision-making. After receiving and reviewing proposals from leading organizations, the Administration selected the National Resource Center for Supported Decision-Making to lead this effort. The National Resource Center began operation October 1, 2014.

National Resource Center for Supported Decision-Making

In partnership with older adults, people with disabilities, attorneys and judges, health care and financial professionals and providers, and others, the National Resource Center will conduct groundbreaking research, create educational programs, and develop multidisciplinary best practices with the goal of advancing policy and practice to establish supported decision-making as a recognized and viable alternative to guardianship.

The National Resource Center’s 5-year action plan includes:

- changing attitudes in the judicial system so that judges recognize and consider supported decision-making as a less restrictive alternative to guardianship;
- creating a multi-disciplinary national dialogue on supported decision-making as a preferred alternative to guardianship;
- analyzing and suggesting modifications to the model Uniform Guardianship and Protective Proceedings Act to recognize supported decision-making as a potential alternative to guardianship;
- identifying and analyzing local, state, and national laws, policies, and practices that promote the use of supported decision-making and those that are

barriers to the acceptance and implementation of supported decision-making;

- implementing supported decision-making best practices across multiple domains, throughout the lifespan, including in the education, health care, financial, and legal systems; and,
- developing and disseminating education, technical assistance, and training material about supported decision-making.

Research Agenda

Kohn and colleagues (2013) argue that the greatest impediment to the full implementation of supported decision-making is the lack of valid and reliable data demonstrating its tie to improved life outcomes. To help fill this gap, the National Resource Center will use multiple methods of data collection and analysis to document the nature and use of supported decision-making by older adults and people with intellectual and developmental disabilities (IDD), focusing on their decision making networks and the ways in which legal, programmatic, and policy systems may enhance or constrain opportunities to practice supported decision-making. The research will seek answers to questions raised by Kohn and others, including:

- How do different people and groups use supported decision-making across life circumstances?
- Does supported decision-making result in measurable improved life satisfaction and outcomes?
- What are the key elements of successful supported decision-making methods?
- What barriers hinder the use of supported decision-making?
- How do existing legal, policy, and program frameworks impact supported decision-making?

To examine supported decision-making, the National Resource Center will use a three-pronged approach. First, it will develop and implement a conceptual model for measuring supported decision-making and its relationship to legal decision making status (e.g., having a guardian or not), self-determination, and quality of life. This work will, in and of itself, be groundbreaking because currently there are no validated measures of supported decision-making. The measures and tools developed will create a template that may be built upon and replicated by other researchers, providers, policy makers, and advocates.

Next, the Center will examine ways people build and use effective supported decision-making systems. This program of study will analyze the

relationship of supported decision-making to factors such as individual capacity and differences over the life course, environmental context and demands, and public and private support mechanisms such as person-centered life planning (e.g., McDonald & Raymaker, 2013). The goal is to validly identify and assess supported decision-making methods that are associated with high quality of life outcomes, reductions in guardianship, and increased self-determination. This information will be used to create a guidebook for best practices in supported decision-making.

Finally, the Center will conduct a 50-state and international review to identify patterns and trends in guardianship and supported decision-making across jurisdictions. This review will include examination and analysis of: (1) existing state laws and policies on guardianship, (2) state and local services and funding means and their relation to decision making (i.e., guardianship and alternatives like supported decision-making), and (3) international supported decision-making laws and policies to catalogue replicable best practices.

Policy and Practice Agenda

The National Resource Center will work to ensure that multidisciplinary policies and practices recognize, encourage, and empower the use of supported decision-making. The Center's policy and practice goals include:

- developing and implementing best practice standards for supported decision-making;
- effectuating policies and procedures in support of supported decision-making; and
- identifying and analyzing local, state, and national laws that advance the use of supported decision-making and those that are a barrier to implementation of best practices in supported decision-making.

Through evidence-based study and analysis, the National Resource Center will identify the elements of successful supported decision-making relationships, such as those that decrease the perceived need for guardianship, increase self-determination, and improve life outcomes. The Center will then incorporate effective supported decision-making methods into outreach, training, and educational materials used in support of supported decision-making best practices.

Of note, the National Resource Center will consider and advance the use of supported decision-making across multiple domains through-

out the life course. To support supported decision-making as a recognized method for increasing self-determination, the Center will advocate for use of supported decision-making best practices in local, state, and national education, employment, health, economic, legal, and other systems to ensure that older Americans and people with IDD may participate fully in all aspects of life throughout the life course, with the support they want and need (e.g., McDonald, et al., in press). Thus, for example, the Center will identify, support, develop, and disseminate educational programs to enhance self-determination with the goal of increased independence (e.g., Powers et al., 2012; Shogren, Wehmeyer, Palmer, Rifenbark, & Little, in press).

Additionally, the National Resource Center will advocate for changes in existing guardianship policy and practice to increase the use of supported decision-making. This effort will include proposals to modify the model Uniform Guardianship and Protective Proceedings Act, to identify supported decision-making as a less restrictive alternative to guardianship and to recognize best practices for supporters and for monitoring, reporting, and resolving disputes. Furthermore, the National Resource Center will work to educate attorneys and judges about supported decision-making by conducting targeted outreach and training.

Another important element of the National Resource Center's activities is the design and implementation of demonstration programs. The Center will bring together and support state-based workgroups to recommend ways to increase supported decision-making recognition and use. One group will be convened in the District of Columbia and comprised of stakeholders of older adults and people with disabilities. This group, facilitated by Quality Trust, will be charged to identify and track the implementation of policies and practices to increase the use of supported decision-making, and to collect and disseminate information about supported decision-making. It also will document success stories, challenges, and changes made to guardianship and supported decision-making law, policy, and practice.

The National Resource Center will support other similar state workgroups. As with the District of Columbia group, state groups will be comprised of stakeholders from the disability and older adult communities who will be charged to collect and disseminate information on supported decision-making and advocate for changes to

policy and practice to increase the use of supported decision-making.

Central to these efforts will be the Center's real-time and accessible web portal, www.SupportedDecisionMaking.Org. The portal will function as a one-stop resource to be a: (a) repository of research, resources, information, and tools; (b) communication platform to share knowledge and best practices; (c) technical assistance vehicle for users to request information, training, and other services; and (d) gateway to external resources and organizations with experience in supported decision-making. The online portal will support state-level advocacy efforts by offering advocates, agencies, and policy makers user-friendly, plain language, and responsive information, training, and technical assistance materials to accelerate the adoption of supported decision-making. It will include Listservs to inform participants about supported decision-making as well as a community of practice virtual learning community, in which participants will post questions, benefit from group problem solving, and share documents and resources.

Education Goals

The National Resource Center will offer interactive and user-friendly information and training materials focused on educating people, professionals, and policy makers about supported decision-making. The Center's education goals include:

- ensuring stakeholder and public access to research and educational material;
- providing customized training programs for individuals, families, professionals, providers, and policymakers;
- developing and disseminating supported decision-making forms, templates, and practice guides; and
- creating a continuing community of practice through in-person and virtual presentations, training material, and social media.

The National Resource Center's web portal, www.SupportedDecisionMaking.Org, will serve as its educational and training hub, providing an accessible, plain language, user-friendly, and interactive clearinghouse focused on supported decision-making. The portal will provide an inventory of reports, research, and practical articles, training, and multimedia resources categorized by topic area, resource type, and intended audience. The portal will translate research findings and educational materials for diverse audiences by making

resources available through a content management system using appropriate writing styles, navigation structures, and accessibility features that will, for example, make it easy for older adults and people with disabilities to access, use, and comprehend the materials (e.g., Blanck, 2014b).

To further ensure wide access to and dissemination of its materials, the Center will establish reciprocal links with its partners' web sites, providing access to each other's resource libraries, research, training, and technical assistance materials. Information will also be solicited, gathered, and disseminated through various social media.

The Center will provide training and technical assistance through multiple means. In addition to in-person presentations at local and national conferences, it will: (a) conduct regular webinars to increase awareness and dialogue about supported decision-making; (b) create and disseminate online toolkits for diverse audiences; (c) provide customized technical assistance to communities committed to supported decision-making; and (d) conduct video conferencing, webinars, and in-person meetings to build consensus on supported decision-making policy, implementation, and research.

Current and archived training, research, and educational materials will be available through www.SupportedDecisionMaking.Org. The portal's community of practice will provide customizable educational resources, training, Listservs, and forums for people with specific questions about facets and applications of supported decision-making. This provision will create additional opportunities to share resources and provide information, education, and assistance across multiple domains and disciplines.

Conclusion

Self-determination is self-sustaining; that is, exercising it over the life course leads to greater opportunities and a greater ability to do so, thereby making people causal agents in their lives, poised and prepared to make life choices to the maximum of their abilities. supported decision-making has the potential to increase the self-determination of older adults and people with disabilities, encouraging and empowering them to reap the benefits from increased life control, independence, employment, and community integration.

The National Resource Center's efforts to change centuries of overly paternalistic guardianship policy, practice, and perception are admittedly ambitious. Society's general preference for plenary guardianship persists (Dinerstein, 2012; Salzman, 2010). However, the Center and its wide array of partners are committed to developing and disseminating evidence-based best practices, with coordinated advocacy and education, to advance a basic human right: that each person has "The Right to Make Choices."

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