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Person-Centered Guardianship: How the Rise of Supported Decision-Making and Person-Centered Services Can Help Olmstead's Promise Get Here Faster

Sean Burke

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PERSON-CENTERED GUARDIANSHIP: HOW THE RISE OF SUPPORTED DECISION-MAKING AND PERSON-CENTERED SERVICES CAN HELP OLMSTEAD’S PROMISE GET HERE FASTER

Sean Burke[†]

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I. INTRODUCTION

Sixteen years after the landmark Supreme Court decision *Olmstead v. L.C. ex rel. Zimring*,¹ traditional models of services and supports for persons with disabilities and older adults are changing. So too are traditional legal tools designed to protect individuals such as guardianship. Although the *Olmstead* case dealt specifically with residential institutions, in recent years, the Americans with Disabilities Act's (ADA) Integration Mandate and *Olmstead* decision have been used to redirect state funding for all types of segregation. This article examines how *Olmstead* principles of self-determination and integration in the community will also bring heightened focus to guardianship and other traditional substitute decision-making practices.

Other commenters have extolled the need for enhanced supported decision-making as an alternative to traditional guardianship and argued that the Integration Mandate of Title II of the ADA provides legal justification for such changes.² This article builds upon such reasoning and picks up on the challenge of Professor Leslie Salzman to develop creative ways of utilizing existing resources so as to build and expand emerging efforts to implement supported decision-making.³ Answers to this challenge require not only legal and practice changes to guardianship but also corresponding investment in services and supports that teach and encourage individuals (and their families, friends, and providers) how to actually make supported decisions.

Part I briefly examines the restrictive nature of guardianship laws and traces the rise of supported decision-making. It argues that supported decision-making reforms may result in better integration, unlike earlier guardianship reforms that have yet to significantly change the way guardianship is practiced.

Part II introduces person-centered concepts, such as the dignity of risk, that suggest self-determination is a fundamental characteristic of integration. It also discusses emerging (if not necessarily new) services such as peer mentoring, self-advocacy, and person-centered planning and how they, as opposed to other types

1. 527 U.S. 581 (1999).

2. See Leslie Salzman, *Re-Thinking Guardianship (Again): Substituted Decision Making as a Violation of the Integration Mandate of Title II of the Americans with Disabilities Act*, 81 U. COLO. L. REV. 157, 157 (2010).

3. *Id.* at 244.

of disability services, enable individuals with intellectual limitations to learn how to make decisions.

Part III argues that as supported decision-making reformers become successful in changing guardianship laws and practices, they must also focus on these person-centered services necessary to teach supportive decision-making skills. Recent changes to the regulation of Home and Community Based Services (HCBS) and the continuing evolution of *Olmstead* make this an especially important time to invest in services and supports that teach and promote decision-making and independence. Long-term care policy makers must do a better job at investing in best practices in these services, instead of simply the traditional “direct care” staff that is the dominant care tool Medicaid services.

II. “I FELT LIKE A PRISONER BUT I DIDN’T DO ANYTHING WRONG.”⁴

In 2012 Margaret “Jenny” Hatch was ordered to leave her home and move across town with unfamiliar people. In her new group “home” she was not allowed to access her phone or Internet to talk with her friends. A twenty-nine-year-old with Down Syndrome, Ms. Hatch’s parents had recently petitioned for guardianship.⁵ The court ordered that Ms. Hatch was incompetent to make her own decisions and appointed a legal guardian empowered to make a whole host of decisions for her—ranging from where she lived, with whom she associated, and all manner of medical care.⁶

4. Jenny Hatch, *Jenny’s Letter*, JENNY HATCH JUST. PROJECT (Nov. 23, 2015), http://jennyhatchjusticeproject.org/jennys_words?q=jenny_speaks.

5. See generally Margaret “Jenny” Hatch et al., *Unjustified Isolation Is Discrimination: The Olmstead Case Against Overbroad and Undue Organizational and Public Guardianship*, 3 INCLUSION 65 (2015) [hereinafter *Unjustified Isolation Is Discrimination*] (summarizing the facts leading up to Ms. Hatch’s legal challenge to the guardianship); see also Theresa Vargas, *Woman with Down Syndrome Prevails over Parents in Guardianship Case*, WASH. POST (Aug. 2, 2013), https://www.washingtonpost.com/local/woman-with-down-syndrome-prevails-over-parents-in-guardianship-case/2013/08/02/4aec4692-fae3-11e2-9bde-7ddaa186b751_story.html.

6. See Petition for Appointment Guardians at 3–4, *Ross v. Hatch*, No. CWF120000426P-03 (Va. Cir. Ct. Aug. 7, 2012) [hereinafter *Hatch Petition*], http://www.jennyhatchjusticeproject.org/docs/justice_for_jenny_trial/jhjp_trial_petition_for_guardianship.pdf (alleging that Ms. Hatch was incompetent to make decisions).

The order came as a shock to Ms. Hatch and her support network. She had been living with close friends, working in a thrift store, and carving out an independent life.⁷ Having recently suffered a bike accident, however, her parents argued that she had poor judgment about her own health and safety.⁸

Like all civil rights movements, the disability advocacy movement has been marked by important legal turning points. Ms. Hatch's case might represent the newest turning point in regard to personal empowerment for decision-making. For the first time in a U.S. guardianship, supported decision-making was used "as an alternative to plenary guardianship for a person with a disability."⁹ Just as importantly, the court noted that the Medicaid-funded services for which she was eligible were integral to providing supported decision-making skills necessary for succeeding independently.¹⁰

What about all the other Jenny Hatches out there without the support of their friends and access to person-centered planning and supported decision-making? The rise of supported decision-making and person-centered guardianship can be successful if there is proper investment in person-centered planning tools.

III. "IN THE BEST INTEREST . . ."¹¹

A. *Healthy, Safe, and Miserable*

The history of twentieth-century guardianship mirrors that of institutionalization. Institutions kept persons with disabilities

7. *Unjustified Isolation Is Discrimination*, *supra* note 5, at 67–70.

8. *Id.*

9. Jonathan Martinis, *Introduction to the Court's Final Order*, http://jennyhatchjusticeproject.org/docs/justice_for_jenny_trial/jhjp_trial_final_order.pdf (last visited May 6, 2016).

10. Final Order at 6, *Ross v. Hatch*, No. CWF120000426P-03 (Va. Cir. Ct. Aug. 2, 2013), http://www.jennyhatchjusticeproject.org/docs/justice_for_jenny_trial/jhjp_trial_final_order.pdf ("Respondent will be able to assist and work with staff provided by the Medicaid Waiver, who will be providing supportive decision making skills and increased self-reliance that will allow her to adapt and succeed independently.")

11. MINN. STAT. § 524.5-313 (2014) (detailing the process for how appointed guardians are to make medical decisions). Most states have similar statutory language directing guardians to make decision in the best interest of the individual.

segregated from society and led to horrific abuse and neglect.¹² State schools such as Willowbrook and Pennhurst evoke horrific images of malnutrition, neglect, mechanical restraint, and other abuses.¹³ Guardians, both public and private,¹⁴ often buttressed institutions by allowing wards to remain in segregated settings while arguing that such placement was in the wards' best interest as the safest option available.¹⁵

As the deinstitutionalization movement sheds light on the abuses in state-operated facilities and institutions,¹⁶ restrictive guardianship has garnered more and more attention.¹⁷ Early reformers to overly restrictive guardianship laws focused on strengthening guardianship standards so as to ensure that wards are protected from abuse and neglect.¹⁸ Oversight over guardians, particularly public guardians, is still a concern in many states;

12. JOHN PARRY, DISABILITY DISCRIMINATION, LAW EVIDENCE, AND TESTIMONY, COMMISSION ON MENTAL AND PHYSICAL DISABILITY LAW 7–18 (2008).

13. See generally The ADA Legacy Project, *Willowbrook Leads to New Protections of Rights*, MINN. GOVERNOR'S COUNCIL ON DEVELOPMENTAL DISABILITIES (Sept. 1, 2013), <http://mn.gov/mnddc/ada-legacy/ada-legacy-moment9.html>; *Remembering an Infamous New York Institution*, NPR (Mar. 7, 2008, 7:00 A.M.), <http://www.npr.org/templates/story/story.php?storyId=87975196>. Although still largely unknown in popular culture, the disgraces of institutionalization have gained recent notice through episodes of *American Horror Story*, Season 2 and the documentary film *Crospy*, which are based on Willowbrook.

14. GORDON H. SMITH & HERB KOHL, GUARDIANSHIP FOR THE ELDERLY: PROTECTING THE RIGHTS AND WELFARE OF SENIORS WITH REDUCED CAPACITY 6–7 (2007), http://supporteddecisionmaking.org/sites/default/files/guardianship_report_elderly_senate_0.pdf (noting that there are generally three types of guardians: family members; non-family private guardians, who are often reimbursed to provide guardianship services; and public guardians are funded and run by state governments).

15. See, e.g., Samuel R. Bagenstos, *The Past and Future of Deinstitutionalization Litigation*, 34 CARDOZO L. REV. 1 (2012) (highlighting examples of parental and guardian-attempted intervention in deinstitutionalization litigation).

16. See generally *id.* at 5–11 (assessing the successes and failures of deinstitutionalization).

17. *Id.* at 35 (analyzing the limitations of Olmstead Integration Mandate arguments' ability to secure individual choice when guardians are granted broad authority to make decisions for such individuals).

18. An analysis of abuse and neglect that occur despite guardianships in place are still very problematic, but outside the scope of this article. For a survey of emerging practices designed to curb neglectful and abusive guardianships, see NAOMI KARP & ERICA WOOD, AARP, GUARDING THE GUARDIANS: PROMISING PRACTICES FOR COURT MONITORING (2007), http://assets.aarp.org/rgcenter/il/2007_21_guardians.pdf.

although there is not overwhelming evidence that large scale abuses are still occurring.¹⁹

Other reforms have dealt with the segregating nature of guardianship, namely, the wholesale removal of decision-making and autonomy from an individual. Current guardianship laws reflect decades of advancement and evolution in the treatment of persons with disabilities.²⁰ The two most common reforms have been less restrictive alternatives and limiting or customizing guardianship powers. The first—a requirement that courts first examine other, less restrictive alternatives to guardianship—is embedded into every state statute.²¹ A primary drawback, however, from a person-centered perspective, is that the types of less restrictive alternatives available are not designed to help an individual consider and make decisions and have informed choice.²²

The other primary reform has been to allow for mechanisms to customize and narrowly tailor guardianship to cover only the aspects of life and decisions that an individual cannot make. For example, a narrowly tailored guardianship could appoint a guardian to make decisions about where a person lives but not give them control over basic medical and health care decisions (or vice-versa). This concept is also problematic when put into actual practice. For persons with intellectual disabilities or declining

19. *Id.* at 2.

20. The reform movement mirrors, in many ways, the deinstitutionalization movement. Litigation before the ADA's integration mandate focused on the abuse and neglect in institutions. Litigation since *Olmstead* has focused on the segregating nature of smaller models of care. *See, e.g.*, Bagenstos, *supra* note 15, at 27–28 (arguing that the new frontier of deinstitutionalization using the ADA and *Olmstead* focuses on smaller facilities that are still institutional in nature, but also employment facilities).

21. *See* AARP PUB. POLICY INST., LIMITED GUARDIANSHIP OF THE PERSON (2008), http://www.americanbar.org/content/dam/aba/administrative/law_aging/Limited_Guardianship_of_the_Person_Chart_authcheckdam.pdf.

22. The common alternatives, including powers of attorney, joint bank accounts, health care directives, and representative payees for dispersing Social Security benefits tend to allow the new decision maker simply to step in and make decisions rather than have the person help the individual make decisions for his or herself to the maximum extent possible. *See also* Salzeman, *supra* note 2, at 177 (“Frequently . . . alternatives for assisting individuals with decisions . . . simply are not readily ‘available.’”).

capacity, it is rare to have the ability to make sound decisions in one area of life and be incompetent in another.²³

Unfortunately, most commentators and advocates agree that these reforms have largely failed to prevent needless guardianships or to promote services and supports for persons who need some help in making decisions.²⁴

None of the reforms, however, have focused on the exact standard or way in which guardians must actually arrive at a final decision. The best interest standard remains the common legal standard of decision-making.²⁵ While best practices suggest guardians should get informed consent and make decisions as the person would, when such a task is difficult, the fallback position of best interest is employed.²⁶ Because guardianship necessarily requires a finding of incapacity, the concept of “whose best interest?” most often becomes what the guardian believes is best. These two concepts, therefore, buttress each other as choices made in the best interest of an individual without legal capacity to make decisions necessarily tend to overemphasize safety.²⁷

Other reforms have required guardians to take a person’s preferences into consideration.²⁸ There is usually no mechanism,

23. *Id.* at 195.

24. *Id.* at 173–82 (detailing how guardianship reforms such as limited guardianships and less restrictive alternatives have not greatly impacted change in guardianship practices).

25. Lawrence A. Frolik, *Is a Guardian the Alter Ego of the Ward?*, 37 STETSON L. REV. 53, 66 (2007) (“[C]ourts appear to expect the guardian to act . . . solely in the best interests of the ward.”). For Minnesota-specific explanations of the different legal standards, see MINN. COUNSEL OF CHIEF JUDGES, CONSERVATORSHIP AND GUARDIANSHIP IN MINNESOTA 30 (2003) [hereinafter CONSERVATORSHIP AND GUARDIANSHIP IN MINNESOTA], http://www.mncourts.gov/mncourtsgov/media/PublicForms/Guardianship%20-%20Conservatorship/01_Guardianship%20Manual/GAC101_Guardianship-and-Conservatorship-Manual.pdf (describing the various standards of substituted decision making).

26. CONSERVATORSHIP AND GUARDIANSHIP IN MINNESOTA, *supra* note 25.

27. In practice, the decision of being moved into or out of a facility (such as a nursing home, assisted, living, or group home) where supervision increases safety but may decrease freedom and choice is often an area where the “safe” decision of staying in the more restrictive setting is the default position, often supported by a doctor and other family members.

28. See CONSERVATORSHIP AND GUARDIANSHIP IN MINNESOTA, *supra* note 25, at 30 (noting that the law requires the guardian to take into consideration *reasonable* wishes and that the determination of reasonable is left to both the guardian, and if necessary, the court).

however, to ensure this consideration takes place and no resources to help a guardian spend the time to actually determine such wishes.²⁹ Furthermore, when having the final say, guardians can take such wishes into account but—under a best interest standard—still remove an individual, like Jenny, from her primary choice of housing, job, and friends.³⁰

In all, none of the reforms have successfully challenged the underlying problems that guardianship finds a person legally incapacitated and entrusts another person to make decisions in his or her best interest.³¹ Thus, if a ward disagrees with a guardian's choice, the adversarial nature established by this regime sets both parties up for conflict.

B. *Emerging Norms in Alternative Decision-Making*

The assumptions underlying guardianship—namely, individuals with intellectual limitations lack capacity—are slowly being challenged and eradicated. In 2006, the General Assembly of the United Nations adopted the Convention on the Rights of Persons with Disabilities.³² It signaled an international shift in the focus and attention for persons with disabilities.

Core to the declaration is the recognition of self-determination and the right to autonomy and personal decision-making. The Convention recognizes “the importance for persons with disabilities of their individual autonomy and independence, including the freedom to make their own choices . . . [and] that persons with disabilities should have the opportunity to be actively involved in decision-making processes about policies and

29. *Id.* (noting that guardians face the tremendous responsibility of making decisions in the ward's best interest).

30. Hatch Petition, *supra* note 6 (finding that is was in Jenny's best interest to have her moved to a group home).

31. See Kim Dayton, *Standards for Health Care Decision-Making: Legal and Practical Considerations*, 2012 UTAH L. REV. 1329, 1347 (“Adult guardianship statutes based on Article V of the Uniform Probate Code generally incorporate the standards in place for guardians of minors, which for all intents and purposes comprise a ‘best interest’ standard.”); Nina A. Kohn et al., *Supported Decision-Making: A Viable Alternative to Guardianship?*, 117 PENN ST. L. REV. 1111, 1117 (2013) (“[I]n recent years, disability rights scholars and advocates, both in the United States and internationally, have challenged the appropriateness and acceptability of guardianship for persons with disabilities . . .”).

32. See generally G.A. Res. 61/106, Convention on the Rights of Persons with Disabilities (Dec. 13, 2006).

programmes, including those directly concerning them.”³³ Internationally, several jurisdictions have developed new alternative decision-making regimes in response to the standards posed by the declaration. Supportive decision-making represents the newest set of emerging reforms and changes to guardianship laws.³⁴ While there is no consensus model, Canada leads the charge as many provinces in the country have some form of supported decision-making laws in place.³⁵

The pioneering legislation on this front was in British Columbia, which established the Representation Agreement Act, allowing the person with a disability to contract with one or more supported decision-makers, called a monitor.³⁶ The Act allows for a broad understanding of capacity, permitting many individuals with intellectual disabilities, who may have been found incompetent under more traditional guardianship laws, greater freedom to determine what areas he or she wants or needs help.³⁷ Templates for such a document allow for detailed descriptions about what choices are in need of support, how those decisions will be made, and with whom the ultimate responsibility for decision-making resides.³⁸

Central to the reforms is the more flexible understanding of legal capacity. They also shift the power dynamic within the relationship and craft a more thorough process that necessarily includes the person with disabilities in the decision. In September 2015, Texas became the first U.S. state to recognize supported decision-making agreements as alternatives to guardianship.³⁹

33. Convention on the Rights of Persons with Disabilities pmbl., ¶¶ n, o, May 3, 2008, 2515 U.N.T.S. 3.

34. See generally Kohn et al., *supra* note 31, at 1120–21 (noting that a single definition of supported decision-making remains elusive, as it can refer to several different models or notions of exactly how an individual with cognitive limitations can be helped by others in making decisions).

35. See *id.* at 1121–24; see also KRISTA JAMES & LAURA WATTS, LAW COMM’N OF ONT., UNDERSTANDING THE LIVED EXPERIENCES OF SUPPORTED DECISION-MAKING IN CANADA (2014), <http://www.lco-cdo.org/capacity-guardianship-commissioned-paper-ccl.pdf> (evaluating the implementation of various supported decision-making laws in different Canadian provinces).

36. Representation Agreement Act, R.S.B.C. 1996, c. 405 (Can.).

37. *Id.* c. 405, § 2.

38. See, e.g., NIDUS PERS. PLANNING RES. CTR. & REGISTRY, MAKING AND REGISTERING YOUR REPRESENTATION AGREEMENT (2014), http://www.nidus.ca/PDFs/Nidus_Form_RA7_all.pdf.

39. TEX. EST. CODE ANN. §§ 1002.0015, 1357.001 (West, Westlaw through

Several similar proposals and reforms are likely to be introduced and implemented in coming years.⁴⁰

C. Ripe for Reform: Why Twenty-Five Years After the ADA Presents a New Opportunity for Guardianship Reform

With nearly forty years of largely failed reforms in guardianship, what makes supported decision-making different from previous attempts?

First, supported decision-making is not just a tweak to guardianship. Fundamentally, it can change the standard by which decisions are made. That is, in a supported decision-making context, there is no “fall back” on the best interest standard such that a guardian can simply impose his or her ideal decision. On the surface, the best interest standard used in most guardianships appears to be the easiest and quickest way to make a decision. By cutting out process, risk, and the skills needed to enable an individual to work through decisions and teach her along the way, the guardian can essentially answer an individual’s concerns with a legal version of “because I said so” using the best interest framework.

Customizing a decision-making process involves time, expertise, patience, and room for trial and error, especially on the “front-end.” However, this work can happen outside the context of the courts, saving time and investment in expensive legal proceedings.⁴¹ Furthermore, once in place, a supported decision-making agreement, designed through person-centered planning principles, may diminish conflict within the ongoing relationship between the individual and his or her support team.⁴² Finally, a

2015); ARC TEX., ALTERNATIVES TO GUARDIANSHIP: SUPPORTED DECISION-MAKING AGREEMENTS 1 (2015), http://www.thearcoftexas.org/site/DocServer/Supported_Decision_Making_For_Families_UPDATED.pdf?docID=4564.

40. MARICA BOUNDY & BOB FLEISCHNER, TRAINING & ADVOCACY SUPPORT CTR., FACT SHEET: SUPPORTED DECISION MAKING INSTEAD OF GUARDIANSHIP: AN INTERNATIONAL OVERVIEW 10 (2013) (noting that some U.S. jurisdictions are actually passing regressive statutes that presume incapacity in certain circumstances while observing some signs of progress on supported decision-making in Florida).

41. *Id.* at 10–12.

42. See JOHN O’BRIEN & HERBERT LOVETT, FINDING A WAY TOWARD EVERYDAY LIVES: THE CONTRIBUTION OF PERSON CENTERED PLANNING 6 (1992) (noting that a function of person-centered planning is to provide a forum to resolve disagreements about what is best for the individual).

decision-making process presents the clear alternative of a less restrictive alternative to guardianship, in a way that no other tool has quite been able to capture.

Externally, the traditional models of long-term services and supports may be changing, in part due to an evolving understanding and application of the ADA's Integration Mandate.⁴³ This evolution may provide more funding and mandates for new types of services that actually teach the skills necessary for supported decision-making. Having seen how little previous reforms have done to change guardianship practice, there may be a consensus forming, especially in advocacy circles, around practical alternatives to guardianship.⁴⁴

There are generally two categories of services and support systems that help individuals develop decision-making skills.⁴⁵ One category focuses on doing things for the individual because the disability or infirmity makes doing the task impossible or impractical.⁴⁶ This category of services includes homemaker services and personal care services, which provide physical assistance for tasks of everyday living.⁴⁷ This may include cueing or supervision to remind or give various cues to help the person with basic tasks.⁴⁸ These may be essential and necessary but not sufficient to live in community settings. Another category of services provides independent living skills, planning, and training that help individuals develop their own skills.⁴⁹ This second category of

43. See Bagenstos, *supra* note 15, at 30–37 (summarizing evolving litigation trends since *Olmstead*).

44. See BOUNDY & FLEISCHNER, *supra* note 40, at 13.

45. See, e.g., Disability Advocates, Inc. v. Paterson, 598 F. Supp. 2d 289, 298, 303–04 (E.D.N.Y. 2009). *Paterson* noted supported housing is “designed for the most independent individuals, who are expected to have good independent living skills and need only minimal staff assistance.” *Id.* at 303. While the adult residential facilities’ purpose was debated between plaintiffs and defendants, the plaintiffs characterized them as institutional facilities and defendants as facilities that provide living quarters as well as other assistive needs such as grooming, dressing, and medication administration. *Id.* at 298.

46. See, e.g., MINN. STAT. § 256B.0659, subdiv. 2 (2014) (defining the types of services, specifically personal care assistant services, covered to help people complete activities of everyday living).

47. *Id.*

48. *Id.* § 256B.0659, subdiv. 4(b)(1)(i).

49. Minnesota provides Independent Living Services, although they are not available for persons with developmental disabilities qualifying for the Developmental Disabilities waiver. See *Independent Living Skills Training*, MINN.

services is concerned with basic safety but is ultimately geared toward helping individuals with intellectual limitations to live as self-determinative lives as possible. Services in this category may also include peer mentoring, self-advocacy, and person-centered planning. Not surprisingly, investment and evolution of this second category of services is still greatly lacking.⁵⁰ Without a concerted effort to change this reality, it is difficult to imagine supported decision-making as a practice or legal regime taking off.

D. For Seniors Too?

Another external factor is demographic shifting. With the looming silver tsunami in the United States, policy makers will feel more pressure than ever to address a large population with significant long-term care needs.

Supported decision-making has less momentum, currently, in the context of senior care and elder services.⁵¹ Some practitioners, however, note the obvious application of supportive decision-making principles to aging populations.⁵² When elders begin to

DEP'T HUM. SERVS., http://www.dhs.state.mn.us/main/idcplg?IdcService=GET_DYNAMIC_CONVERSION&RevisionSelectionMethod=LatestReleased&dDocName=id_002236 (last updated May 29, 2015) (showing that independent living skills are available only on the BI, CAC, and CADI waivers—not the Developmental Disabilities waiver).

50. While some services may be paid for with waiver funds, individuals still find it hard to locate an actual provider able and willing to provide such services. The purchase of person-centered planning services, for example, was only recently added to Minnesota's HCBS programs. See *Disability Services Division Announcement for Licensed Providers to Consult on Person-Centered Planning Practices*, MINN. DEP'T HUM. SERVS. (Nov. 18, 2014), http://www.dhs.state.mn.us/main/idcplg?IdcService=GET_DYNAMIC_CONVERSION&RevisionSelectionMethod=LatestReleased&dDocName=dhs16_190923.

51. Most practical applications of supported decision-making have involved persons with intellectual and developmental disabilities, although supported decision-making for elders is an emerging area. See *Supported Decision-Making Encouraged at National Aging and Law Conference*, A.B.A. (Nov. 5, 2015), http://www.americanbar.org/news/abanews/aba-news-archives/2015/11/supported_decision-m.html. New tools being developed include checklists, designed to better screen for supportive decision-making candidates. See AM. B. ASS'N, TEST A NEW PRACTICE TOOL—REDUCE THE NEED FOR GUARDIANSHIP AND SUPPORT DECISION-MAKING, http://www.americanbar.org/content/dam/aba/administrative/mental_physical_disability/PRACTICAL.authcheckdam.pdf (last visited Mar. 8, 2016).

52. See, e.g., Tina Campanella, *Supported Decision-Making in Practice*, 3 INCLUSION 35, 35–39 (2015) (discussing how to implement person-centered

lose cognitive functions, many family members, social service systems, and medical systems rely on guardianship as the default mechanism for surrogate decision-making.⁵³ The supported decision-making agreement regimes in Canada and Australia, with their flexible treatment of capacity, allows for a far greater number of people who may otherwise have been shuttled into overly restrictive guardianships.⁵⁴ The other benefit for elderly individuals is the ability to craft truly customized agreements that guide both them and their support network into a reasonable process for making decisions.

One main difference in introducing supported decision-making to elder populations is how it will differ or change current, less restrictive alternatives that are already available. Is it duplicative of options already available, such as common estate planning tools like power of attorney healthcare directives? Growing concerns about power of attorney abuse, however, have called into question the lack of safeguards with this type of surrogate decision-making.⁵⁵

Because it relies on contractual-type agreements without court oversight, supported decision-making may elicit the same general criticisms unless it can prove that it is more effective than other strategies at helping individuals and their support networks identify exactly what an elder wants. More data is needed about how

supported decision-making practices for both older adults and persons with disabilities).

53. See, e.g., Joseph A. Rosenberg, *Poverty, Guardianship, and the Vulnerable Elderly: Human Narrative and Statistical Patterns in a Snapshot of Adult Guardianship Cases in New York City*, 16 GEO. J. ON POVERTY L. & POL'Y 315, 323 (2013) (“Guardianships usually occur as a last resort or a default in the absence of proper planning to avoid a guardianship, which can be done with advance directives such as a power of attorney, living will, health care proxy, or other arrangements such as a trust.”).

54. See generally *Understanding the Lived Experience of Assisted and Supported Decision-Making in Canada*, CAN. CTR. ELDER L., http://www.bcli.org/sites/default/files/Supported_Decision_Making_Background.pdf (last visited May 6, 2016); DEP'T HUMAN SERVS. STATE GOV'T OF VICTORIA, SUPPORTING DECISION MAKING 14 (2012), http://www.dhs.vic.gov.au/__data/assets/pdf_file/0011/690680/dsd_cis_supporting_decision_making_0212.pdf (describing the principle of assumed capacity and how even persons with some limitations should be enabled to make decisions by the supporter).

55. See, e.g., LORI A. STIEGEL, DURABLE POWER OF ATTORNEY ABUSE FACT SHEET (2008), http://www.americanbar.org/content/dam/aba/migrated/aging/about/pdfs/durable_poa_abuse_fact_sheet_consumers.authcheckdam.pdf (documenting abuse by attorneys-in-fact).

effective supported decision-making is at engaging individuals with limited capacity in the process, and whether it both improves quality of life and adequately protects an individual from maltreatment.⁵⁶ Some limited empirical evidence suggests that, when considering the appointment of an alternative decision maker, elders may care about who is chosen much more than how that person ends up making decisions.⁵⁷ More research is needed to examine whether supportive decision-making processes, and their open nature, would be more advantageous to existing mechanisms.

IV. TWINKIES FOR BREAKFAST? “IT’S MY HUMAN RIGHT AND YOU CAN’T STOP ME”⁵⁸

In a letter published soon after her case, Ms. Hatch described the painful effects of being isolated in the group home. She stated:

I was placed in a group home. I did not want to be there. I told everyone that I was not happy and did not like it. I just wanted to go home . . . I was not allowed to go to my job at the Thrift Store. I worked there for almost [five] years. I wasn’t allowed to have my friends or coworkers visit or even call me. I wasn’t allowed to have my cell phone or computer. . . . I was told I had rights at the group homes. But that wasn’t true. [My guardian] took them away. It was like I didn’t matter. Like I didn’t exist. [My guardian] took away my rights, my choices, my independence. . . . I was kept away from my community, my church, and my friends. I kept telling everyone I was unhappy but no one listened to me.⁵⁹

While the *Hatch* case may represent a more extreme example of an overbroad guardianship,⁶⁰ it captures the adverse relationship

56. See Kohn et al., *supra* note 31, at 1128–29 (arguing the lack of empirical data for supported decision-making must be remedied).

57. *Id.* at 1141 n.123 (citing one study surveying older adults about appointing substitute medical decision-makers).

58. Elspeth Slayter Recevik, *Twinkies for Breakfast: Implementing the Dignity of Risk for Adults with Intellectual Disability*, DISABILITYINFO.ORG (Feb. 12, 2014) [hereinafter *Twinkies for Breakfast*], <http://blog.disabilityinfo.org/?p=3928> (reflecting on the experience of reasoning with her adult sister about the health implications of her life’s decisions).

59. *Hatch*, *supra* note 4. Originally, a company called Jewish Family Services (JFS) was appointed guardianship over Jenny. Later, her parents replaced JFS. In this letter, Jenny refers specifically to JFS when discussing her guardian.

60. *Unjustified Isolation Is Discrimination*, *supra* note 5 (noting that the original

model that most guardianships naturally establish. Because one party is given the ultimate “best interest” veto, any decision whereby there might be tension becomes a possible battleground for a power struggle.

Commentators, professionals, and especially well-meaning guardians and family members have wrestled with the tension that occurs in guardianships when individuals with disabilities are given greater freedom in self-determination. Elspeth Slayter, sister to an adult with intellectual disabilities, candidly recalls her frustrations in debating with her sister about the damaging effects of a high-sugar diet.⁶¹ Slayter admitted that her own idealistic notion of supporting her sister’s independence was pushed to the limit with a simple confrontation in the grocery store, which evolved into a power struggle about what was “best” for her sister.⁶²

Standing her ground, her sister insisted on purchasing Twinkies and used her personal advocacy skills to force a showdown in the middle of the snack-food aisle.⁶³ In the end, Slayter was able to find some compromise, allowing for the Twinkies in addition to a healthier option.⁶⁴

Such a compromise may be able to be negotiated on the fly, but what about more difficult life decisions? What about the practicality of having a showdown every time the ward and guardian disagree? What happens when the argument is not about diet or exercise but about dating, sexual relationships, or wanting to raise a family?⁶⁵

Slater’s experience illuminates the difficulty of putting person-centered planning and self-determination principles into actual practice. When a ward and guardian disagree, how will the ultimate decision be made? Who will make it? What processes or resources are in place for both the guardian and the ward to sufficiently process the decision? Will there be room (and time) for compromise and self-determination? Even the most well-

emergency guardianship that was granted over Jenny Hatch was one of the more extreme examples of overbroad guardianship).

61. *Twinkies for Breakfast*, *supra* note 58.

62. *Id.*

63. *Id.*

64. *Id.*

65. *See, e.g., In re Guardianship of Dameris L.*, 956 N.Y.S.2d 848 (N.Y. Surr. Ct. 2012). The case presents a classic power struggle between parent and daughter over her ability and judgment in parenting and having a family.

intentioned support of such decision-making can tend to fall back on more restrictive notions of well-being and best interest, if only for the sake of convenience and time.

Many caretakers of individuals with intellectual disabilities or diminished capacity cite the fatigue and strain that daily care can take on their lives.⁶⁶ However, developing a “system,” whereby everyone knows the basic context of who makes what decisions and how such decisions get made, may have the practical effect of easing this “care” burden.

A. *Dignity of Risk*

The very nature of guardianship is paternalistic. It takes away autonomy for health and safety. The underexplored area, however, is the health impacts of taking away all decision-making capability.

Learned helplessness is endemic to institutionalization. In the early 1970s, disability advocate Robert Petscke began articulating a concept of dignity of risk—the ability to make decisions that have natural consequences.⁶⁷ Steadily, research has followed these observations. As medical studies have consistently shown links between ability to make decisions and physiological health,⁶⁸ many legal commentators have openly questioned the way in which guardianship and the determination of lack of capacity harm individuals.⁶⁹ Alternatives that provide more autonomy naturally come with more risk, which leads to several questions: Who is willing to pay for the risk? What do these alternatives look like and how will they better balance safety and autonomy? How do they work and who will pay for them? Who will bear a share of the risk—beyond the individual? Are service providers, states, or others to be

66. See generally Richard Schulz & Paula R. Sherwood, *Physical and Mental Health Effects of Family Caregiving*, 44 J. SOC. WORK EDUC. 105 (2008) (studying the high incident of caregiver fatigue).

67. See generally Robert Perske, *The Dignity of Risk and the Mentally Retarded*, 10 MENTAL RETARDATION 24 (1972), http://mn.gov/mnddc/ada-legacy/pdf/The_Dignity_of_Risk.pdf.

68. See generally Salzeman, *supra* note 2, at 169–70 nn.30–31 & 33 (summarizing research showing poor psychological health outcomes associated with a lack of self-determination in everyday decisions and larger life choices).

69. See, e.g., *id.* at 196–220 (establishing that providing guardianship can, in some instances, embody a prima facie claim of violation of the ADA’s Integration Mandate); see also *id.* at 168–69 (arguing that legal findings of incapacity add to the damage and harm of an individual via loss of control and isolation).

held accountable if something goes wrong? Who has the time and the patience to allow for risk-taking?

B. Person-Centered Planning

Person-centered planning is a process developed to address life planning and goals for persons with intellectual and developmental disabilities. As institutions for these individuals were being closed and community services being developed, it became clear that plans and mechanisms needed to be created to help individuals with disabilities adjust to life in the community. Early models included meetings, templates, and resources to help people think through basic problems.⁷⁰ For example, an individual with developmental disabilities might create a Planning Alternative Tomorrows of Hope (PATH) or Making Action Plan (MAP) in order to obtain the ultimate goal of getting a job.⁷¹ Currently, more and more, the concept of planning is being recognized as a proactive way to anticipate potential conflict and pre-determine exactly *how* tough decisions might be made, if and when the need to make these decisions arises.⁷²

The resources needed for the development of such a plan, and the expertise necessary to help a family create a plan, will vary on a case-by-case basis. Ultimately, the growth of person-centered tools is tied to other service options. In many states, increasing the availability of person-centered planning services is constrained by the lack of employment, recreational, and residential options that individuals would “choose” using person-centered planning.⁷³ With

70. See generally CONNIE LYLE O'BRIEN & JOHN O'BRIEN, *A LITTLE BOOK ABOUT PERSON CENTERED PLANNING* (1998).

71. PATH and MAP are person-centered planning tools designed to help an individual and their support network get on the same page about goals and how to achieve them. See *Person Centered Planning*, INCLUSIVE SOLUTIONS, <http://inclusive-solutions.com/person-centred-planning/#typesofplanning> (last visited May 6, 2016).

72. In practice, person centered planners may actually act like mediators, helping the individual better communicate with the other members of the decision-making team and helping team members see how their actions may be inhibiting the individual's feeling of independence and self-determination. See *Twinkies for Breakfast*, *supra* note 58 (discussing how the compromise process developed in the area of food choices may be helpful for when even more important decisions arise).

73. See JOHN O'BRIEN, *PERSON-CENTERED PLANNING AND THE QUEST FOR SYSTEM CHANGE* 11–12 (2013), <http://www.inclusion.com/downloads/obrienarchive>

recent changes to HCBS requirements,⁷⁴ states may increasingly invest in person-centered planners and self-advocate mentors, including peer specialists who are still fledgling.⁷⁵

C. *Role of Peers and Self-Advocacy Movement*

The self-advocacy movement gained traction in the deinstitutionalization movements of the 1960s and 1970s.⁷⁶ As a practice, it may look different but generally includes a group of persons with disabilities gathered to share fellowship and strategies for advocating for more rights in respect to their everyday life. Generally, a self-advocacy group may also include a non-disabled ally to help provide guidance and shape to the group.⁷⁷ To this point, the connections between integration success and self-advocacy have not been the subject of intensive study, but many practitioners have noted the significant influence that self-advocacy can have on self-determination.⁷⁸

/System%20Change%20and%20Leadership/Person-Centered%20Planning%20in%20System%20Change.pdf.

74. See DEP'T HEALTH & HUMAN SERVS., FACT SHEET: SUMMARY OF KEY PROVISIONS OF THE 1915(C) HOME AND COMMUNITY-BASED SERVICES (HCBS) WAIVERS FINAL RULE 2 (Jan. 10, 2014), <https://www.medicaid.gov/medicaid-chip-program-information/by-topics/long-term-services-and-supports/home-and-community-based-services/downloads/1915c-fact-sheet.pdf> (discussing the HCBS rule defining home and community-based settings).

75. See GWEN ORLOWSKI & JULIE CARTER, JUSTICE IN AGING, A RIGHT TO PERSON-CENTERED CARE PLANNING 6–8 (2015), http://justiceinaging.org/wp-content/uploads/2015/04/FINAL_Person-Centered_Apr2015.pdf (discussing Center for Medicare and Medicaid's requirements regarding informed choice and the necessity of involving professional person-centered facilitators).

76. See The ADA Legacy Project, *The Self Advocacy Movement*, MINN. GOVERNOR'S COUNCIL ON DEVELOPMENTAL DISABILITIES (May 1, 2014), <http://www.mn.gov/mnddc/ada-legacy/ada-legacy-moment17.html>.

77. For a general overview of the importance and role of an advisor, see BILL WORRELL, PEOPLE FIRST: ADVICE FOR ADVISORS (1988), https://testaucd.files.wordpress.com/2012/10/advice-for-the-advisors_bill-worrell.pdf and *The Self-Advocacy Movement*, CTR. ON HUM. POL'Y, <http://thechp.syr.edu/chp-archives-the-self-advocacy-movement/> (last visited Mar. 27, 2016).

78. For an overview of the current state of self-advocacy in the United States' intellectual and developmental disabilities community, see JOE CALDWELL ET AL., INST. ON DISABILITY & HUMAN DEV., ENVISIONING THE FUTURE: ALLIES IN SELF-ADVOCACY FINAL REPORT (2012), https://testaucd.files.wordpress.com/2012/10/2012allies_report_web1.pdf.

Access to self-advocacy and peer resources for persons with intellectual disabilities, however, remains sparse.⁷⁹ In Ms. Hatch's case, Medicaid-waiver funded staff helped her and her new guardians develop a supported decision-making plan. However, in this situation, it is not clear that Ms. Hatch had access to a peer group or other self-advocates from whom to draw support and to learn. This vital resource, already widely used in the mental health and chemical dependency services, is still waiting for significant development.⁸⁰

V. "A GUARDIAN IS SUPPOSED TO HELP ME REACH MY GOALS"⁸¹

One of Ms. Hatch's great insights in reflecting on her experiences was the fact that as a person with a disability, she needed some help but nothing like the guardianship process she was put through. She wanted someone to help her reach her goals but not control her life.⁸² Guardianship places a focus and emphasis on the protection of the ward and the ward's property rather than on helping the ward reach his or her goals.⁸³ Jenny's statement is, unfortunately, a critique on what guardianship is and a call to either reform or offer alternatives.

A. *Beyond an Integrationist Strategy: Responding to the Challenge of Social and Economic Equality.*

Testifying as an expert witness in the *Hatch* case, Robert Dinerstein stated, "[A] guardian's job, actually, even when appointed, is to use what's called 'substituted judgment': that is to make the judgment that the individual would make if he or she were able to express that judgment rather than say the best interest or what the guardian thinks would be right for the guardian."⁸⁴

Relying in part on this principle, the court ordered a limited guardianship "with the ultimate goal of transitioning to the

79. *Id.* at 6.

80. *Id.* at 10–13.

81. *Hatch*, *supra* note 4.

82. *Id.* (expressing her own recognition for needing help for some things in her life but also wanting to make her own decisions).

83. Kohn et al., *supra* note 31, at 1119–20 (discussing the concerning aspect of guardianship where needs and wants are not taken into account).

84. Final Order, *supra* note 10, at 5.

supportive [decision-making] model.”⁸⁵ It is not clear if the same result would follow in every jurisdiction. Minnesota’s guardianship law, for example, does specially allow for substituted judgment—but only in narrow circumstances.⁸⁶ Otherwise, guardians must make decisions in the best interest of the individual. Legally, as supportive decision-making grows as an alternative, it remains to be seen if jurisdictions will modify statutes to require supportive decision-making as an alternative, or if they will change the fundamental standard of best interest to substituted and supportive—or some combination thereof. As legal reforms inevitably occur, however, it is likely that without provision of services that teach supportive decision-making skills, such reforms will have as much effect as previous guardianship reforms. What is needed, therefore, is a holistic approach, such as the one advocated by commentators who have focused on social and economic equality as primary factors for driving integration.⁸⁷ As person-centered planning becomes more recognized as a legitimate practice, its aims should be towards becoming a social science. Investment in such services should be seen as a way to combat the inequality, while leading to better data about the overall effectiveness of supported decision-making and the other inequalities that prevent individuals from actually making the choices that are discovered via the person-centered planning process.

B. *Role of Medicaid Funding in All of These Services*

Medicaid funding for HCBS services has varied widely in terms of promoting and leading to integration.⁸⁸ In 2011, the Centers for

85. *Id.*

86. See MINN. STAT. § 524.5-411(e) (2014) (noting the factors tantamount to substituted judgment the court can consider in its approval of the guardian’s exercise of powers in regard to making gifts or other donative transfers).

87. Responding to several advancements in civil rights protections for persons with disabilities, law professor Mark Weber has argued that significant social change cannot come through legal advancements alone and an integrationist (ADA Integration Mandate) approach is fundamentally limited. See Mark C. Weber, *Disability and the Law of Welfare: A Post-Integrationist Examination*, 2000 U. ILL. L. REV. 889, 904–08. Adhering to this argument, the future of supported decision-making likely depends on both legal advancements and economic investment in new services and practices.

88. See, e.g., ERIC CARLSON & GENE COFFEY, NAT’L SENIOR CITIZENS LAW CTR., 10-PLUS YEARS AFTER THE OLMSTEAD RULING 3 (2010), <http://>

Medicare and Medicaid Services (CMS) published a draft rule defining a home and community-based setting. Finalized in 2014, the rule represents the first federal attempt to define and require person-centered planning in the provision of Medicaid services.⁸⁹

The rule encourages integration in part by using indicia of institutionalization captured in *Disability Advocates, Inc. v. Paterson*.⁹⁰ In *Paterson*, private group homes funded by Medicaid were challenged as institutional and the court used a thorough analysis of the setting's characteristics to reach a conclusion that the group homes were not the most integrated setting for the people living in them.⁹¹

The characteristics noted in *Paterson* are prominently featured in the CMS rule, including autonomy and self-determination.⁹² The rule requires that HCBS settings must be "integrated in and [must support] full access of individuals receiving Medicaid HCBS to the greater community, including opportunities to seek employment and work in competitive integrated settings, engage in community life, control personal resources, and receive services in the community."⁹³

Two specific parts of the rule stand out as potentially influencing supported decision-making. The setting must "[o]ptimize[] . . . not regiment, individual initiative, autonomy, and independence in making life choices, including but not limited to, daily activities, physical environment, and with whom to interact . . . [and] [f]acilitate[] . . . individual choice regarding services and supports, and who provides them."⁹⁴ While it remains to be seen how states will implement these standards, there is arguably now a legal incentive to invest in person-centered

www.thescanfoundation.org/sites/default/files/nsclc_olmstead.pdf (noting a bias in Medicaid toward institutional rather than HCBS programs and the various limitations of such HCBS programs).

89. See 42 C.F.R. § 441.301(c)(1) (2014).

90. 598 F. Supp. 2d 289, 289 (E.D.N.Y. 2009).

91. *Id.* at 321–31 (analyzing the institutionalized characteristics of the group homes that plaintiffs wanted to move out of).

92. See, e.g., 42 C.F.R. § 441.301(c)(1) (requiring a person-centered planning process that is led, when possible, by the individual); see also *id.* § 441.301(c)(4)(vi) (mandating that provider-controlled settings must grant all individuals the ability to set their own schedules, have access to visitors and food at any time, and have privacy in their own units or rooms).

93. *Id.* § 441.301(c)(4)(i).

94. *Id.* § 441.301(c)(4)(iv)–(v).

planning and other supportive decision-making services so as to help service providers comply with these requirements.

C. *Conclusion: Educating Decision Makers and Empowering the Next Generation*

Individual examples of success using person-centered planning techniques abound throughout service systems. Kicked out of four group homes, Mark and his guardians were finally connected with a person-centered planning process that began to get at the root issues for his behavioral incidents.⁹⁵ Minnesota's growing emphasis on person-centered planning provides a unique look at the correlation between person-centered planning and supported decision-making. The Minnesota *Olmstead* plan now defines person-centered planning as an organized process of discovery and action meant to improve a person's quality of life:

Person-centered plans must identify what is important to a person (e.g., rituals, routines, relationships, life choices, status and control in areas that are meaningful to the person and lead to satisfaction, opportunity, comfort, and fulfillment) and what is important for the person (e.g., health, safety, compliance with laws and general social norms). What is important for the person must be addressed in the context of his or her life, goals and recovery. This means that people have the right and opportunity to be respected; share ordinary places in their communities; experience valued roles; be free from prejudice and stigmatization; experience social, physical, emotional and spiritual well-being; develop or maintain skills and abilities; be employed and have occupational and financial stability; gain self-acceptance; develop effective coping strategies; develop and maintain relationships; make choices about their daily lives; and achieve their personal goals. It also means that these critical aspects cannot be ignored or put aside in a quest to support health and safety or responsible use of public resources.⁹⁶

95. See *Housing Options Best Practices Forum*, MINN. HOUSING BENEFITS 101, <http://mn.hb101.org/video/HousingOptions.04.20.15.htm> (last visited Apr. 27, 2016).

96. MINN. OLMSTEAD SUBCABINET, PUTTING THE PROMISE OF *OLMSTEAD* INTO PRACTICE: MINNESOTA'S *OLMSTEAD* PLAN 32 (Aug. 2015), http://www.dhs.state.mn.us/main/idcplg?IdcService=GET_FILE

Unfortunately, this definition is more aspirational than actualized. Data on person-centered outcomes remain sparse.⁹⁷ While practitioners have forged trails, funding barriers remain as many state Medicaid systems continue favor institutional models rather than HCBS models of care.⁹⁸ Plus, simply investing in more HCBS services does not ensure quality of services or that such service providers will be focused on enabling independence and integration of the people they serve.⁹⁹ Staff members trained and paid to provide person-centered services, however, would help the individual achieve the goals described in the defining of person-centered planning.

One way to ensure person-centered planning happens is to give consumers—persons with disabilities—more control in the direction (including hiring) of their staff. Consumer choice models reflect a growing recognition that persons with disabilities have better outcomes and success when they are allowed to take an active role in choosing how their services and supports work.¹⁰⁰

Supported decision-making can both inform and be better developed through HCBS programs. Consumer choice is still a daunting goal for many persons, and supported decision-making could help make it more attainable. Self-advocacy and peer mentoring services can provide vital support for individuals who have never known what it is like to be empowered to make their own informed and independent decisions.

Perhaps the best evidence of Ms. Hatch's ability to participate in decision-making has been her acceptance of a new title: international disability rights advocate. Shortly after moving home, she helped create the Jenny Hatch Justice Project, and now is a self-advocate and national advocate on these issues.¹⁰¹ She is using her

&RevisionSelectionMethod=LatestReleased&Rendition=Primary&allowInterrupt=1
&noSaveAs=1&dDocName=dhs16_196300.

97. See generally Crystal A. Hughes, *The Benefits and Barriers to Person Centered Planning for Adults with Developmental Disabilities*, at 4 (2013), http://sophia.stkate.edu/cgi/viewcontent.cgi?article=1193&context=msw_papers.

98. See CARLSON & COFFEY, *supra* note 88, at 3.

99. *Id.* (noting that HCBS provided in some facilities such as assisted living, may have less regulatory oversight than traditional institutional models and do not ensure the care provided is any less institutional in nature).

100. See, e.g., Dennis L. Kodner, *Consumer-Directed Services: Lessons and Implications for Integrated Systems of Care*, INT'L J. INTEGRATED CARE 1, 3 (2003).

101. See generally NAT'L RESOURCE FOR SUPPORTED DECISION-MAKING, <http://supporteddecisionmaking.org> (last visited Apr. 27, 2016) (formerly the

experience to educate her peers about their rights and, in her words, ensure that “what happened to me doesn’t happen to someone else.”¹⁰²

Jenny Hatch Justice Project).

102. Hatch, *supra* note 4.