

SOCIAL SECURITY ADVISORY BOARD
STATEMENT ON THE SUPPLEMENTAL SECURITY INCOME PROGRAM

Public Law 104-193 requires that members of the Social Security Advisory Board (**the Board**) be given an opportunity, either individually or jointly, to include their views in the Social Security Administration's annual report to the President and Congress on the Supplemental Security Income (**SSI**) program. We have asked the Social Security Administration (**SSA**) to include in this year's annual report the following discussion of the Representative Payee (**rep payee**) program administered by SSA for adult recipients on SSI.

During the last year the Board has reviewed the Social Security Administration's rep payee program as well as similar programs administered by state courts and other agencies. The Board recognizes that SSA has made enormous efforts to administer the program effectively. Nonetheless, the Board is unanimous in its belief that SSA is and will remain ill-equipped to manage the current workload adequately. The courts and other agencies that manage similar programs have similar difficulties.

There is good reason to believe that the current program does not serve many very elderly SSA beneficiaries who might be helped by the program; and, if the projections by SSA's research office are even roughly correct,¹ the number of people to be served will expand rapidly over coming decades as retiring baby boomers age and come to need assistance managing their finances.² Currently unmet needs as well as this increase may well add to current difficulties in adequately managing the rep payee program. Stagnant budgets intensify this problem.

The Board concludes that core changes are needed. Despite hundreds of pages of policy and regulations, the way SSA determines whether a rep payee is needed is arbitrary. The responsibilities of the rep payee are onerous, particularly in the SSI program. Although additional procedures have been introduced to monitor the program, the size of the rep payee program makes meaningful oversight impossible.

¹ Anguelov, C. E., Ravida, G., & Weathers, R. R., II. (2015, May). Adult OASDI Beneficiaries and SSI Recipients Who Need Representative Payees: Projections for 2025 and 2035. *Social Security Bulletin*, volume 75(2). (Social Security Administration, Office of Retirement and Disability Policy). Retrieved July 13, 2016, from <https://www.ssa.gov/policy/docs/ssb/v75n2/v75n2p1.html>.
Social Security Bulletin, Vol. 75, No. 2, 2015.

² While this paper considers the SSI program, projections include rapid growth in the Old-Age and Disability Insurance Program.

The existing program involves an all or nothing substitution of judgment regarding beneficiaries' capacity to manage their own resources, instead of assessment of need, coupled to a continuum of support, with a goal of helping beneficiaries to remain as independent as possible. SSA must remain involved in the rep payee system. It already collects the data, determines program eligibility, and issues the benefit. But SSA is not structured to administer the program alone, to determine the need for assistance, to design the nature of the assistance, or to monitor the performance of those providing guidance to those managing beneficiaries' funds or in administering payments.

This paper looks at SSA's statutory authority, the selection process for rep payees and the different responsibilities of rep payees in SSI and in SSA's other programs. It also provides an overview of the make-up of the current SSI rep payee program for adult beneficiaries. Although there are troubling issues in the SSI children's program, touched on in the 2014 SSI statement, this paper focuses on adult beneficiaries. Finally, this report explores a growing movement to replace programs that "care for" individuals with those which tailor support on a case-by-case basis and help beneficiaries retain as much autonomy as possible.

THE CURRENT REPRESENTATIVE PAYEE PROGRAM

In 2014, there were approximately 7 million adult SSI recipients in the disability and old-age programs. SSA determined that roughly one quarter of all beneficiaries – 1.85 million— could not manage their own benefits and appointed others to manage their funds³. The Social Security Act authorizes the Commissioner to determine whether a beneficiary, regardless of legal competency or incompetency, is better served if the social security benefit is paid to another person, or an organization.⁴ This broad authority was added long before the creation of the Title II disability insurance or the Title XVI SSI programs, where the majority of rep payees are currently assigned. Rather, it was included in the 1939 Amendments which extended benefits to wives of retired workers, widows and dependent children of deceased workers and authorized the Board (now Commissioner) to assign someone other than the legally entitled beneficiary to receive and manage their benefits.

SSA regulations provide that a rep payee will be appointed when SSA determines that beneficiaries are unable to manage or direct the management of their own benefits.⁵ The regulations do not indicate

Selected Abbreviations

- Social Security Advisory Board (**Board**)
- Supplemental Security Income (**SSI**)
- Social Security Administration (**SSA**)
- Representative Payee (**rep payee**)
- Convention on the Rights of Persons with Disabilities (**CRPD**)

³ Social Security Administration, Office of Retirement and Disability Policy & Office of Research, Evaluation, and Statistics. (2015, October). *SSI Annual Statistical Report, 2014*, Table 7. Retrieved July 13, 2016, from https://www.ssa.gov/policy/docs/statcomps/ssi_asr/2014/ssi_asr14.pdf.

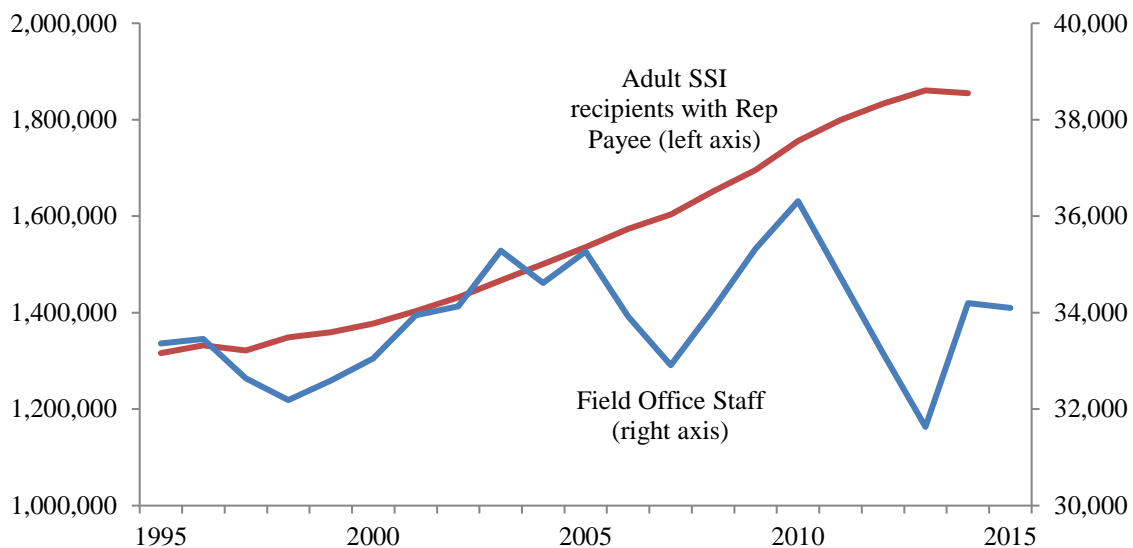
⁴ Social Security Act Amendments of 1939, 42 USC § 405(j).

⁵ 20 CFR § 416.601 (1995).

what constitutes an inability to manage benefits. They indicate that the determination will be made after considering medical evidence and/or statements from relatives, friends and other people in a position to know and observe the beneficiary. The decision-making process is largely discretionary. As a result, it is difficult to challenge decisions individually or to evaluate them programmatically. The determination process currently does not require input from the beneficiary, or representation on the beneficiary's behalf. There is no competency or due process hearing. The regulations require only that notice be sent to the beneficiary after the agency has decided to assign a rep payee. The notification is a letter from the agency with the name of the appointed rep payee, and information about the beneficiary's appeal rights. There is no requirement that the agency verify the beneficiary has received and understands the agency decision.⁶ There is also no current procedure to automatically reexamine the need for a rep payee on a periodic basis.

The determination of whether a beneficiary needs a rep payee has been added to the long list of responsibilities given to field offices which are often understaffed and over worked. The little time devoted to consideration of whether a person should lose their right to manage their own benefits has been further reduced as the number of SSI recipients and therefore the number of SSI recipients assigned rep payees has increased, while the number of field offices has declined and staffing has been stagnant or reduced during recent years.

Adult SSI Recipients with a Rep Payee and Field Office Staffing Levels, 1995-2015

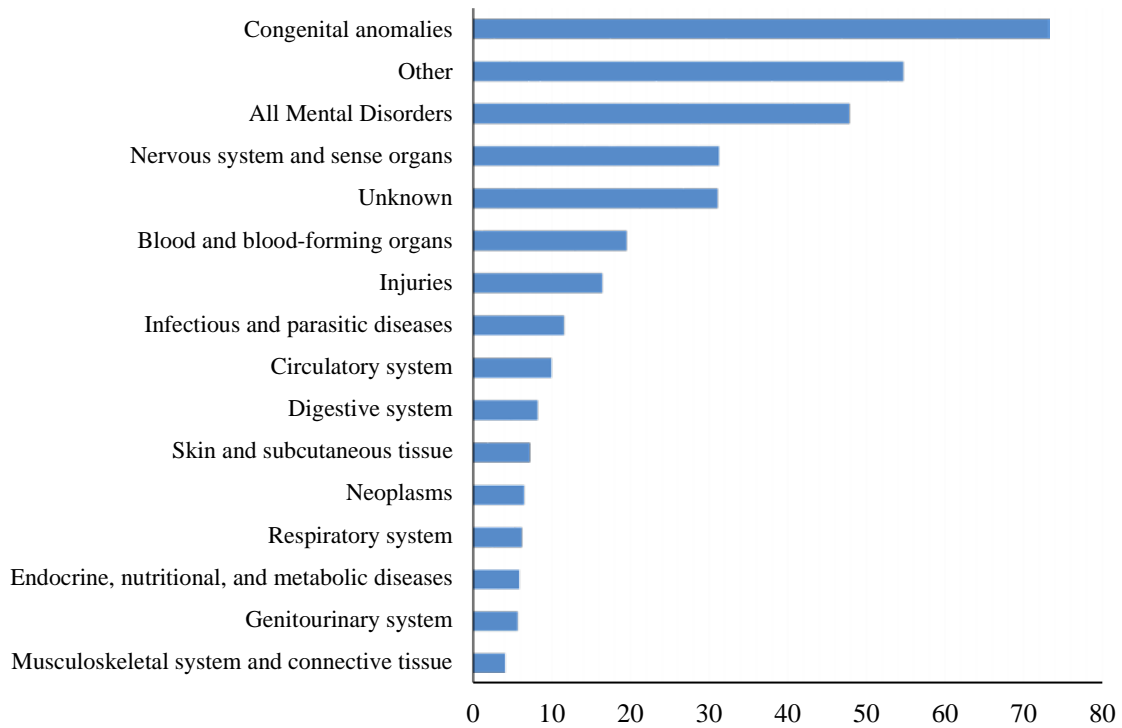


Source: Social Security Administration, Office of Budget and SSI Annual Statistical Report, 2014.

⁶ 20 CFR § 416.630 (2006).

SSI adult recipients with certain impairments are more likely to have rep payees than those with other conditions. As shown in the tables below, recipients with congenital anomalies are assigned rep payees at the highest rate, and those in a catch-all “other” category come in second.

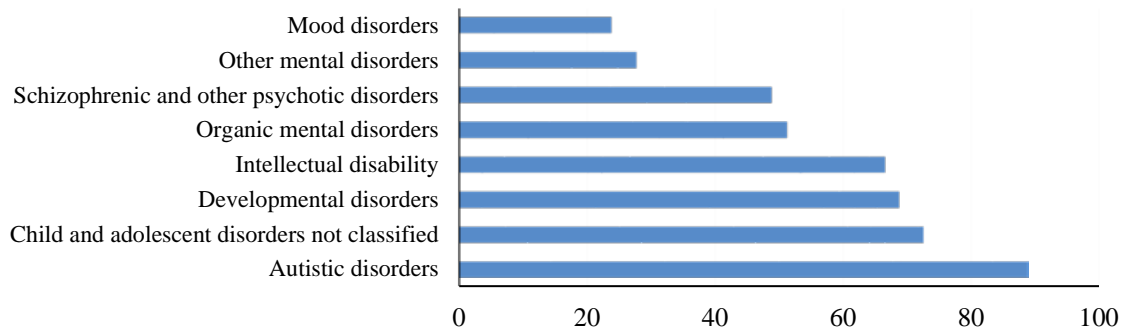
Percentage of SSI Adults with a Rep Payee by Disability Category, 2014



Source: Social Security Administration, SSI Annual Statistical Report, 2014.

The third most likely impairment where a rep payee is assigned is under the categories of mental disorders, which encompasses several sub categories as reflected in the chart below.

Percent of SSI Adults That Have Mental Disorder Diagnosis with Rep Payees, by Type of Diagnosis

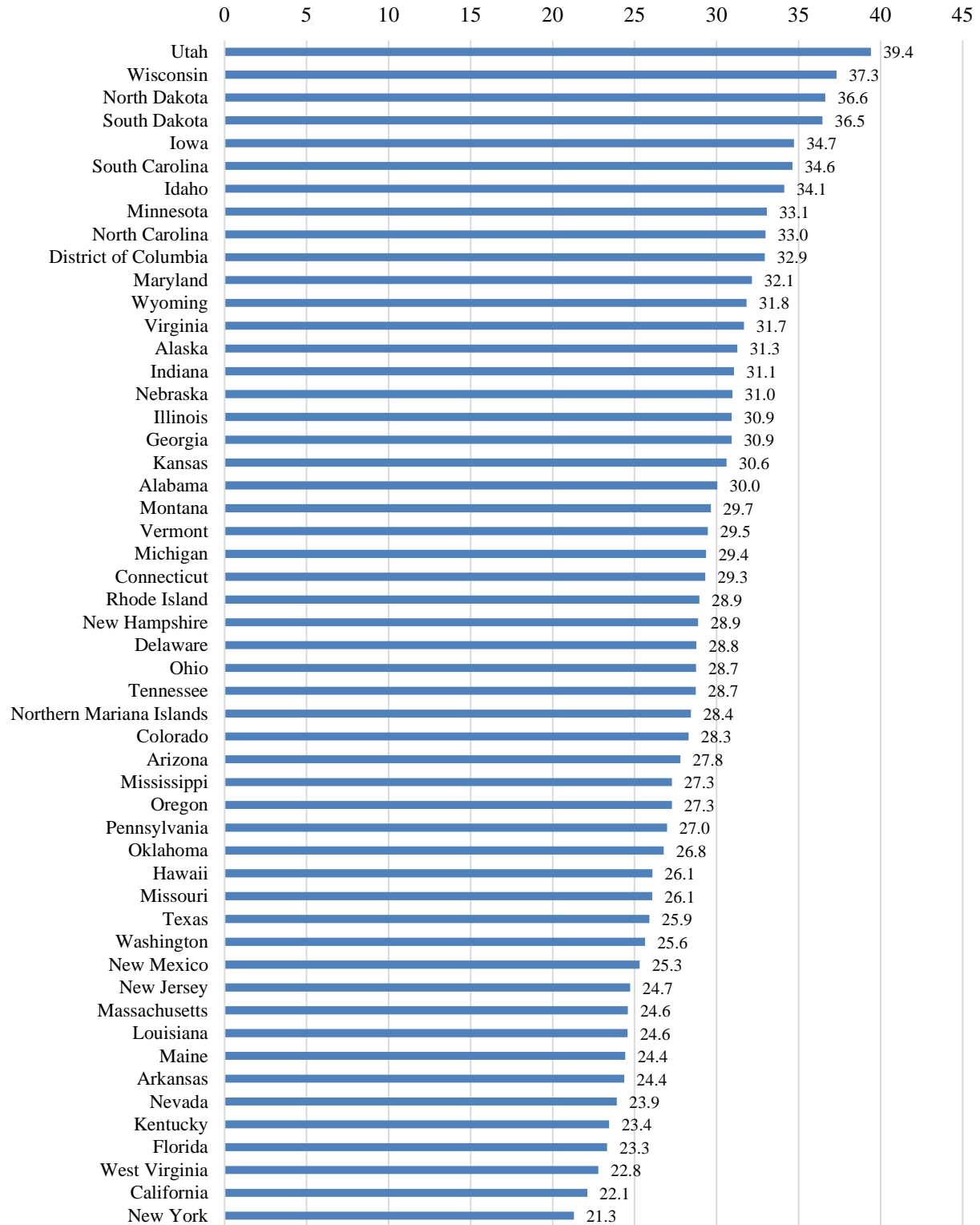


Source: Social Security Administration, SSI Annual Statistical Report, 2014.

These impairments are broadly categorized and difficult to analyze. Assignment of a rep payee does not appear to be based on a person’s medical diagnosis. Eighty-nine percent of those with” autistic disorders” are assigned rep payees, leaving open the question of how the remaining 11 percent manage their benefits. Forty-nine percent of those with schizophrenic and other psychotic disorders were assigned rep payees, leaving open a question of what additional capabilities the remaining 50 percent of recipients had. More importantly, autistic disorders and psychotic disorders all occur on a continuum, suggesting that a continuum of assistance, rather than a binary decision to leave recipients alone or remove all control is fair or appropriate.

The following table shows that the determination to assign a rep payee may be as much tied to the geographical location of the recipient as it is related to the person’s underlying impairment. Without more analysis it is difficult to assess whether some offices are over-assigning rep payees, some failing to address recipient’s needs, or, less probably, the incidence of need varies widely from place to place. It is possible that the availability of rep payees or that the availability of medical services in an area influences the decision. These enormous geographic variations cry out for additional study to reveal whether rep payee appointment determinations are consistent and accurate. These questions are of profound importance as appointment of rep payees may unnecessarily curb or flat out violate beneficiary rights to exercise self-determination in the disposition of their Social Security benefits. The decision to take away control of a person’s finances should be based on a competency hearing for the recipient, or, at a minimum, a review by program officials of medical certification that addresses the specific issue of capability to manage benefits

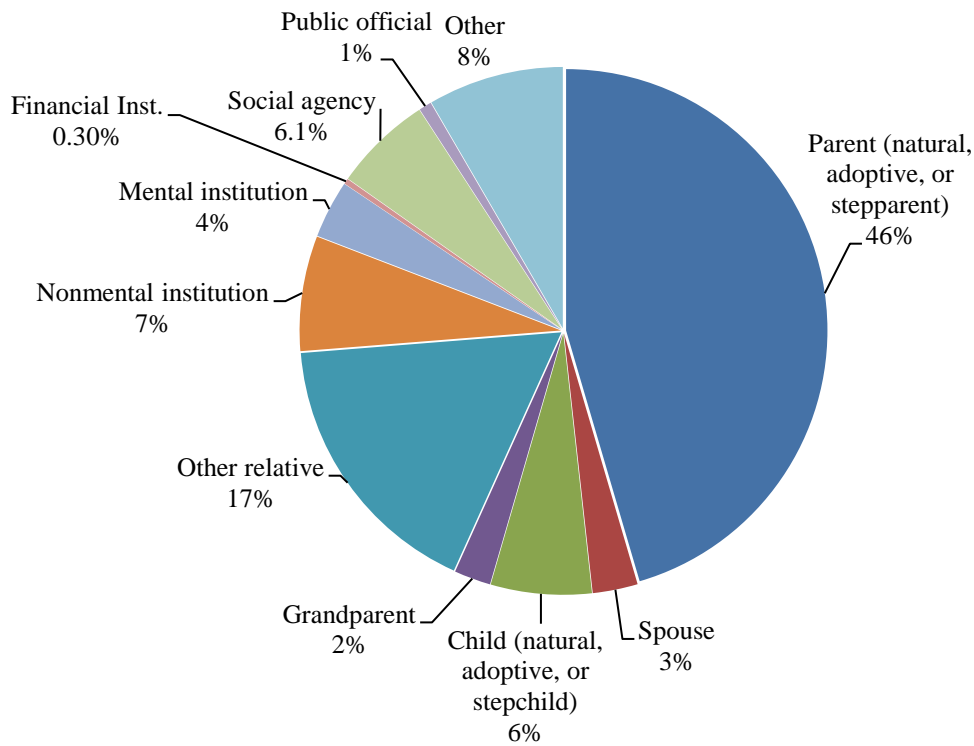
Percent of Adult SSI Recipients with Rep Payees in December 2014, By State



Source: Social Security Administration, Office of Research, Evaluation and Statistics

Most rep payees for adult SSI recipients are also adults, usually parents. SSA gives first preference to family members, provided they are not judged unsuitable (although what constitutes ‘unsuitability’ is also vague.) Problems may arise as parental rep payees age. In such cases, it is essential either to prepare the SSI recipients themselves to learn to take over management of their benefits or to identify alternate payees.

**All SSI Adults with Rep Payees,
By Type of Payee**



Source: Social Security Administration, SSI Annual Statistical Report, 2014.

The Job of the Rep Payee in the SSI Program

The job of the rep payee, as set forth in the regulations can be time consuming for the rep payee and is invasive for the beneficiary. The rep payee is charged with using the beneficiary’s payments to pay for food, shelter, clothing, medical care and personal comfort items.⁷ Rep payees handling SSI recipient’s benefits have additional duties relative to rep payees managing benefits under other Social Security programs. As SSI is a program of last resort and consequently affected by other payments, benefits or assistance, the rep payee is obligated to report to SSA any changes in the beneficiary’s circumstances, including living situation, marriage, return to work efforts, and gifts over \$20.00 and other kinds of in-kind support and

⁷ 20 CFR § 416.640 (2011).

maintenance changes. The rep payee must also remain aware of the amount of the beneficiary's savings and resources, and report to SSA if they exceed the \$2,000 threshold for individuals and \$3,000 for couples, thresholds above which recipients become ineligible for benefits.

Finding volunteers is especially difficult in the SSI program as managing funds can require the payee to allocate funds among such essentials as food, rent and basic utilities and to stay abreast of the beneficiary's living circumstances and changes in financial condition. Errors that result in overpayments that the agency determines the rep payee should have recognized may be charged to the rep payee. When SSA believes that a rep payee has misused funds, it may refer the case for criminal prosecution. The penalty upon conviction for a payee's misuse of funds may be a fine of up to \$250,000, imprisonment up to 10 years, or both.⁸ Although such penalties are seldom, if ever, imposed, these potential punishments may hamper recruitment of volunteers.

A NEW APPROACH

Periodic media reports of abuse by rep payees have triggered calls for additional monitoring and oversight, for more thorough background searches, and for more data on complaints about the rep payee, but few have called into question the process for determining whether complete denial of autonomy to recipients is necessary and whether there might be alternatives that provide graduated assistance and preserve some measure of authority and responsibility for SSI recipients. In the next section of this report the Board reviews an alternative approach to stimulate public discussion.

The Concept of Supported Decision Making

The current rep payee process is one of *substituted* decision making. This substituted decision making occurs not only in SSI but also in the Old Age Survivors and Disability Insurance programs as well. Because the rep payee for an SSI recipient must monitor resource and asset limits the rep payee's responsibility is greater and also more intrusive than it is in the OASDI programs. The beneficiary is dependent on the rep payee and unless the rep payee allows it, the recipient has no voice in determining how the SSI benefit is spent. Recipients with little cognitive function may be unable to participate in a discussion about how their benefits are spent, but many SSI recipients retain some capacity to engage in the decision making process. Indeed, preserving and developing these capacities can be not only comforting but also help in the recovery process.⁹ Under a supported (or shared) decision making model, beneficiaries could be provided assistance to enable them to make their own financial decisions to ensure fulfillment of their basic needs (food, clothing, shelter, etc.) in ways that are consistent with their preferences. The amount and nature of assistance depends on individual need and can be

⁸ Social Security Administration. (2010, April 26). *Social Security Handbook*, § 1617.8. Retrieved July 13, 2016, from https://www.ssa.gov/OP_Home/handbook/handbook.16/handbook-1617.html.

⁹ See Kurtz-Dougherty, S. (2014, June 24). Money management for the severe and persistently mentally ill. *Theses and Dissertations*. Retrieved July 13, 2016, from <http://rdw.rowan.edu/etd/348>.

adjusted as a person's health improves or worsens.¹⁰

The concept of shared or supported decision making is not new. A 1977 article in Hospital & Community Psychiatry, described a process for assessing the kind of support system necessary to help clients meet their material, personal-care and psychosocial needs. The first step is the determination of what the client is able to do. Next comes a determination of the activities with which the client needs assistance. The final step identifies the supports that would help the individual either remain more self-sufficient or become more autonomous.¹¹

This approach has gained acceptance in medical practice. Michael J. Barry, MD, Medical Director of Mass General's Stoeckle Center for Primary Care Innovation has studied medical decision making since 1983. Mass General now has its own Health Decision Sciences Center, and is one of the leaders in the implementation of shared decision making. The goal is to have patients and their doctors evaluate the medical evidence and available options and then consider the patient's values, priorities, and preferences, before jointly deciding on a treatment plan.

The establishment of assisted living facilities was built on a similar supported assistance philosophy, providing support as needed but encouraging residents to maintain autonomy. Since the first assisted living facility opened in Portland, Oregon in 1981 thousands more have been built.¹² Assisted living is now the most favored and fastest growing long-term care option for seniors in the United States.¹³ Advocates for supported decision making are becoming increasingly vocal in the disability movement. In the 26 years since enactment of The Americans with Disability Act a generation has grown up with its protections, community integration and emphasis on self-determination. Challenges in guardianship cases suggest that courts are also seeking ways to minimize interventions in beneficiary decisions by authorized representatives under a guardianship order.

The legal system has also begun to incorporate a different approach in guardianship cases. A seminal case for advocates of supported decision making involves a guardianship case in Virginia. Jenny Hatch, a young woman with Downs Syndrome, was removed from the home where she had been staying. Her family petitioned the court for full guardianship, including the authority to decide where Ms. Hatch would live and whether to give or withhold medical

¹⁰Dinerstein, R. D. (2012). Implementing Legal Capacity Under Article 12 of the UN Convention on the Rights of Persons with Disabilities: The Difficult Road From Guardianship to Supported Decision-Making. *Human Rights Brief*, 19(2). Retrieved July 13, 2016, from http://supporteddecisionmaking.org/sites/default/files/implementing_legal_capacity_article_12_un_convention.pdf.

¹¹ Test, M. A., & Stein, L. I. (1977, August). Special Living Arrangements: A Model for Decision-Making. *Hospital & Community Psychiatry*, 28(8), 608-610.

¹² For background on emergence of assisted living facilities, see Marak, C. (n.d.). History of Assisted Living: How Assisted Living Started in United States. Retrieved July 13, 2016, from <http://www.assistedlivingfacilities.org/resources/history-of-assisted-living/>. See also Gawande, A. (2014). *Being Mortal: Medicine and What Matters in the End*. Metropolitan Books.

¹³ See Marak, C., History of Assisted Living: How Assisted Living Started in United States.

treatment. Initially, the judge ordered placement of 28 year-old Hatch in a group home where her cell phone and laptop were taken away from her and she was not allowed to see friends. Over the next year Hatch was moved around to several group homes but at her petition hearing about a year later, the judge determined that while Hatch, with an IQ of 50, did need a guardian to help her make decisions, he considered her preferences and designated friends to act as a guardian, with the goal of helping her become more independent. The legal questions involved determining whether Hatch needed a guardian, and if so, who best would serve in that role. However, disability advocates said the case was much more than that as it addressed the civil death that occurs when a person is stripped of decision-making authority over his or her own life, and it signified a shift in attitude towards providing assistance and integration.¹⁴

The passage of The Supported Decision-Making Agreement Act¹⁵ made Texas the first state to recognize supported decision-making agreements as a less restrictive alternative to guardianships. The Act defines supported decision making as:

A process of supporting and accommodating an adult with a disability to enable the adult to make life decisions, including decisions related to where the adult wants to live, the services, supports, and medical care the adult wants to receive, whom the adult wants to live with, and where the adult wants to work, without impeding the self determination of the adult.

This agreement allows people with a disability who face the possibility of guardianship to choose assistants who will help them with decision making that might otherwise be difficult for them to manage alone. The use of such agreements, the potential additional workload for courts, the need for court oversight, and research into the impact this will have on the community are important issues to follow in the next few years as Texas' supported decision- making Act takes shape in different agreements.

The Convention on the Rights of Persons with Disabilities

The idea of substituting one person's decision-making power for another's has also been challenged as a matter of human rights law in the international human rights treaty, the Convention on the Rights of Persons with Disabilities (**CRPD**). Article 12 in this treaty provides a legal foundation on which to challenge decisions by medical or social service personnel that deprives a person of decision-making autonomy. The Article requires states to abolish guardianship laws based on substitute decision-making in favor of a system of supported decision-making. The treaty was adopted by the United Nations General Assembly on December 13, 2006, and as of June 2016 there are over 160 signatories. It was signed by the United States

¹⁴ Vargas, T. (2013, August 3). Woman with Down Syndrome wins right to reject guardianship. *Portland Press Herald*. Retrieved July 13, 2016, from http://www.pressherald.com/2013/08/03/woman-with-down-syndrome-wins-right-to-reject-guardianship_2013-08-03/.

¹⁵ Supported Decision-Making Agreement Act, Tex. Estate Code § 1357.002.

on June 30, 2009.¹⁶ On December 4, 2012, the United States voted on the resolution to ratify the treaty, which had passed through the Foreign Relations committee with bipartisan support, but ratification fell six votes short of the two-thirds majority on the Senate floor.¹⁷

Should the United States ratify the treaty in the future, it would assume an obligation to move from a legal system that measures and judges mental capacity, and appoints a guardian to make substituted or best interest decisions, to a system that affirms the legal capacity of persons, and provides them with the supports necessary to make their own decisions to the maximum feasible extent. In practical terms, this means for each guardianship determination and perhaps rep payee assignment, an individual assessment would be necessary to determine what supports are needed, how to best provide them, how long they will be necessary, and a process for periodic review by a legal authority.¹⁸

Supported decision making is appealing in concept as it embraces individual autonomy, an underlying goal of the disability movement. However, additional research and testing is needed.¹⁹ Measures are necessary to determine if a decision for support accurately reflects the beneficiary's desires and fulfills their needs. Research is needed on the quality and clarity of the supported decisions, the types and kinds of supports that prove to be helpful, and whether there are adequate corrective procedures in place to assist in determining capacity (and to redetermine capacity as it changes). Further studies are needed on the psychological impact of learning money management skills, and whether such learning builds confidence and assists people with cognitive disabilities in their ability to learn, or whether it overwhelms and confuses. Much of the research needed is not to test the underlying principle of supported decision-making but rather about how and when to adjust the supports, and what indicators reveal the beneficiary is struggling. Close attention should be paid to developments in countries that have ratified CRPD and are testing the supported decision making model. But attention to what is going on elsewhere is no substitute for research here, especially as the projections warn that the workload here will continue to grow.

¹⁶ United Nations Treaty Collection: Convention on the Rights of Persons with Disabilities. (2008, May 3). Retrieved July 13, 2016, from https://treaties.un.org/Pages/ViewDetails.aspx?src=IND&mtdsg_no=IV-15&chapter=4&lang=en.

¹⁷ Roll Call votes was 61 Yeas, 38 Nays and 1 not voting; see U.S. Senate Roll Call Votes 112th Congress – 2nd Session (Resolution of Ratification Treaty Doc. 112-7). (2012, December 4). Retrieved July 13, 2016, from http://www.senate.gov/legislative/LIS/roll_call_lists/roll_call_vote_cfm.cfm?congress=112&session=2&vote=00219.

¹⁸ Kohn, N. A., Blumenthal, J. A., & Campbell, A. T. (2013, April 29). Supported Decision-Making: A Viable Alternative to Guardianship? *Penn State Law Review*, 117(4), 1111. Retrieved July 13, 2016, from [http://www.pennstatelawreview.org/117/4%20Final/4-Kohn%20et%20al.%20\(final\)%20\(rev2\).pdf](http://www.pennstatelawreview.org/117/4%20Final/4-Kohn%20et%20al.%20(final)%20(rev2).pdf).

¹⁹ Salzman, L. (2007). Guardianship for Persons with Mental Illness - A Legal and Appropriate Alternative? *St. Louis.U. Health Law & Policy Journal*, 4(279). Retrieved July 13, 2016, from http://supporteddecisionmaking.org/sites/default/files/guardianship_for_persons_with_mi.pdf.

CONCLUSION

Despite efforts to improve the rep payee process, and considerable oversight by agency officials the current rep payee process is unsatisfactory. The key shortcomings are inappropriate procedures for appointing rep payees, onerous requirements on rep payees, and inadequate monitoring. A new process is clearly needed. While supported decision-making must be tested further, and researched in more depth, the starting point should be recognition that the goal is self-determination and independence. It is difficult for risk-averse bureaucracies to quickly and successfully adopt such major changes as a shift from the current rep payee system to one of graduated assistance. On the other hand, research and testing in a controlled environment may never reveal the challenges and unintended consequences that would result from universally adopting the approach that we propose herein. We recognize that properly calibrating and scheduling changes over time in the degree of support and intrusiveness of the system will be difficult and may lead to mistakes. However, there may be no substitute to "learning by doing" and gradually improving the system through feedback from beneficiaries, their relatives, and friends who remain concerned about beneficiaries' welfare. This should be weighed against the fact that high paternalism of the current process intended to "keep people safe" has created its own set of failures.

Supported decision-making peels back an element of protection. The amount peeled back will depend on the needs, skills and learning process for each person. This model will require shared responsibilities from other agencies and organizations as SSA does not have the personnel or the expertise to provide this kind of individual attention. It will also require a significant Federal funding increase, but this should not be viewed as a deal-breaker. The Social Security Advisory Board will continue to look at the current rep payee process, and at how to best design an alternative.

Henry J. Aaron, Chair

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