Testimony of Paul S. Appelbaum, MD to the Subcommittee on Social Security House Committee on Ways and Means February 7, 2017

Good morning. I am Dr. Paul Appelbaum, Elizabeth K. Dollard Professor of Psychiatry, Medicine & Law at Columbia University, and I am grateful for this opportunity to testify regarding the work of the committee that I chaired for the National Academies of Science, Engineering and Medicine: the Committee to Evaluate the Social Security Administration's Capability Determination Process for Adult Beneficiaries (hereafter "the Committee"). The Committee's report was issued in March 2016

(http://iom.nationalacademies.org/Reports/2016/Informing-Social-Securitys-Process-for-Financial-Capacity-Determination.aspx). Because the work of the Committee concluded when the report was issued, my testimony is offered as a private citizen, not as a representative of the National Academies.

The Committee was constituted at the request of the U.S. Social Security Administration (SSA), and given the following charge:

1. Familiarize itself with SSA's current policy and procedures for capability determinations for adult beneficiaries;

2. Provide an overview of the capability determination processes in at least three similar benefit programs (at least one government program and one private-sector program);

3. Compare SSA's program to these other programs; and

4. Provide recommendations to improve the accuracy and efficiency of SSA's policy and procedures for capability determinations.

The Committee included members with expertise in psychiatry, neurology, social work, law, bioethics, health policy, neuropsychology, and behavioral science. To inform its report, the Committee took testimony from SSA, relevant experts, and health service and advocacy organizations, and reviewed the relevant research literature.

SSA asked the Committee, in pursuit of its charge, to focus on those beneficiaries receiving disability benefits (i.e., not other types of benefits, such as old age or survivor's benefits). SSA provides vital financial support to more than 17 million disabled Americans. Of that group, approximately 5 million have been deemed—by virtue of youth or mental or physical impairment-incapable of managing or directing the management of their benefits. A representative payee has been appointed to receive and disburse SSA payments for these beneficiaries to ensure that their basic needs for shelter, food, and clothing are met. The importance of creating as accurate a process as possible for incapability determinations is underscored by the consequences of incorrectly identifying recipients either as incapable when they can manage their benefits or as capable when they cannot. On one hand, given the importance of individual autonomy in decision making in a democratic society, deprivation of the right to manage one's money—which ensues from a finding of incapability—represents a serious infringement on liberty that should occur only when absolutely necessary. Conversely, failure to identify beneficiaries who are incapable of managing their funds means abandoning a vulnerable population to potential homelessness, hunger, and disease. Needless to say, neither error is desirable.

After reviewing the evidence that it gathered and the testimony that it took, the Committee made six recommendations that it believed would improve SSA's procedures for determining financial capability and the need for appointment of a representative payee.

Evidence for Determining Financial Capability

The Committee endorsed SSA's requirement for "lay" evidence of beneficiaries' financial performance in making capability determinations as consistent with the conclusion that evidence of real-world financial performance is the most reliable basis for making such determinations. However, the reliability of third-party informants varies. In addition, most informants, including professionals, are not trained specifically in assessment of financial performance and competence and would benefit from detailed direction as to the type of information that is helpful to SSA in making capability determinations. Currently, SSA provides little formal guidance to medical professionals and no formal guidance to other informants. The Committee therefore recommended that: "The U.S. Social Security Administration (SSA) should provide detailed guidance to professional and lay informants regarding the information it would find most helpful for making capability determinations, including (1) information about specific aspects of beneficiaries' financial performance in meeting their basic needs and, when information about performance is unavailable, about their financial competence; and (2) information that would enable SSA to judge the validity of the evidence provided by the informant."

With respect to financial performance, SSA's guidance to all informants could be based on the questions it currently provides to field officers. There are times when no or very limited information is available about a beneficiary's financial performance—for example, when the person has had no funds to manage or when no third-party informant with knowledge of the person's performance can be identified. In such cases, evidence of financial skills assessed in a controlled setting may need to be used to inform capability determinations. Guidance pertaining

to financial competence could include questions such as those developed by Canada's Pension Plan, along with requests that the basis for informants' answers be specified.

To enable SSA to judge the validity of information from informants, it is important that evidence provided for capability determinations specify how well and for how long the informant has known the individual and the nature of their relationship. It is also important to specify the extent to which the informant's judgment is based on: (1) observed behavior; (2) the individual's self-report; (3) information from collateral informants, and the perceived quality of these informants; and (4) in the case of professionals, the individual's medical record and the assessments of other health care professionals (including other physicians, psychologists, social workers, and nurses). Such specification of the basis for the evidence provided will allow for greater understanding of the quality of the evidence regarding financial capability.

Systematic Identification of Adult SSA Beneficiaries at Risk for Financial Incapability

Three recommendations addressed the need for and mechanisms by which systematic identification of individuals who are risk for financial incapability could occur.

Risk Criteria

Reliance on diagnostic criteria alone for determining financial (in)capability is inadequate for a number of reasons, including the likelihood of identifying too many people as incapable in some diagnostic categories and missing people in others, a central concern raised by the prior OIG-SSA reports, which indicated a concern about under-identification of beneficiaries in need of representative payees. Identification of easy-to-apply, efficient approaches, including the development of screening criteria, that could be incorporated into the disability application process to identify people at high risk for incapability would be valuable in helping to ensure that

potentially incapable beneficiaries receive further evaluation. In response to this concern, the Committee recommended that: "The U.S. Social Security Administration should create a data-driven process to support the development of approaches, including screening criteria, for identifying people at high risk for financial incapability."

SSA has the opportunity, whether through the development of formal screening criteria or other approaches (e.g., identifying risk markers to inform the judgment of field officers), to improve its ability to identify beneficiaries who may lack financial capability. The committee envisions the development of a model based on existing data, such as age, gender, impairment code assigned by SSA, and education level, to identify predictors of incapability. The resulting model could be refined and its reliability and validity improved through pilot projects involving samples of beneficiaries who would undergo more detailed assessments of capability. Prior to large-scale implementation, the success of the resulting approach in identifying incapable beneficiaries who would not otherwise have been found could be tested.

Dual Beneficiaries

A 2012 SSA-OIG report indicated that more than 6,000 people who were receiving benefits from both the SSI and SSDI programs had been assigned a representative payee in one program but not the other. In addition, SSA beneficiaries also may receive benefits from another federal agency, such as Veterans Affairs or the Office of Personnel Management (OPM). While acknowledging the potential technological, legal, and procedural challenges to data sharing, the committee concluded that sharing information about incapability determinations within SSA and among relevant federal agencies could increase the likelihood of each agency's identifying potentially incapable beneficiaries. Agencies could then use the information to trigger their own capability assessments of beneficiaries identified in this way. Hence the Committee

recommended that: "The U.S. Social Security Administration (SSA) should ensure intraagency communication regarding capability determinations within its different programs. In addition, SSA, the U.S. Department of Veterans Affairs, and other relevant federal agencies should assess the extent of inconsistency in the identification of beneficiaries who are incapable among persons receiving benefits from more than one agency. Based on the findings of this assessment, the relevant agencies should explore mechanisms to facilitate ongoing interagency communication regarding the capability of beneficiaries."

OPM, for example, uses computerized matching to identify beneficiaries who receive other federal benefits. Although such matching is used primarily to analyze whether benefits from other programs may affect OPM benefits, a process of this sort can also provide information that indicates whether other programs have identified the beneficiary as having impaired capability.

Responding to Changes in Capability Over Time

Many psychiatric and cognitive conditions are characterized by progression or fluctuation over time in the presence, severity, and nature of symptoms. Such changes suggest the value of periodic reassessment of a beneficiary's capability. SSA's lack of a formal process for periodic review of a beneficiary's capability is a significant weakness. Some mechanism for periodic reassessment is needed to ensure that beneficiaries with fluctuating, deteriorating, or improving financial capability are classified accurately. Accordingly, the committee recommended that **"The U.S. Social Security Administration should develop systematic mechanisms for recognizing and responding to changes in beneficiaries' capability over time."**

For disability beneficiaries, SSA procedures call for periodic continuing disability reviews (CDRs). Although CDRs provide an opportunity for capability (re)assessments, their

purpose is to identify any changes (improvements) in the medical basis for a beneficiary's disability award. Thus, even if the CDRs were to occur on schedule, they would not fully serve the purpose of reassessment of financial capability. SSA could apply the same principle used in the CDR process to develop an analogous process for recognizing and responding to changes in capability over time. Reassessments initially could be targeted toward (1) beneficiaries who had been determined to be incapable but who might improve over time as their conditions or environmental supports changed; and (2) beneficiaries who, although capable, were at risk for becoming incapable as their condition progressed or their environment changed. As screening criteria or other systematic methods for identifying people at high risk for financial incapability were developed, they might be used to broaden the target population for periodic reassessment.

In addition, beneficiaries, family members, representative payees, and professionals who were likely to come into contact with beneficiaries could be alerted systematically to notify SSA if they believed that beneficiaries' capability had changed. SSA might also implement a process to survey payees and/or beneficiaries periodically, similar to that of OPM, integrating screening questions that could trigger the need to further investigate the beneficiary's financial capability.

Supervised Direct Payment

By their nature, SSA capability determinations are dichotomous; that is, beneficiaries are either capable or incapable of managing or directing the management of their benefits. As noted, however, a beneficiary's capability may change as a result of progressive or temporary diminution or improvement in his or her financial competence and performance over time. When information available about a beneficiary's financial performance is insufficient to determine the need to appoint a representative payee, the use of a supervised direct payment option may be helpful. Under such a model, benefits are paid directly to the beneficiary, but an individual is

designated to supervise the beneficiary's expenditures. Reassessment after a trial period during which the beneficiary's use of benefits is observed and assessed permits more accurate determination of the beneficiary's capability in indeterminate or borderline cases.

Supervised direct payment may have other advantages. By adopting a supported decisionmaking model, supervisors can provide guidance and instruction to beneficiaries on managing their benefits and help respond to the challenges posed by the fluctuations in some beneficiaries' financial competence and performance. Supported decision making encourages beneficiaries' expression of preferences, beliefs, and values; allows collaboration in decision making; and provides opportunities for beneficiaries to make independent decisions whenever possible. Appropriate use of this approach may provide a beneficiary with greater control over his or her life than would be the case for someone without such support. Supervised direct payment may enable some beneficiaries who might otherwise require the appointment of a representative payee to manage or direct the management of their benefits to meet their basic needs, thus maximizing their decisional autonomy. For these reasons, the committee recommended that: **"The U.S. Social Security Administration should implement a demonstration project to evaluate the efficacy of a supervised direct payment option for qualified beneficiaries.**"

"Qualified beneficiaries" refers to two groups of individuals. The first is beneficiaries who may be incapable of managing or directing the management of their benefits but for whom there is insufficient information regarding financial performance to render a determination. The second is beneficiaries who are determined by SSA to be incapable, but who either display financial performance in some but not all areas of benefit management or successfully manage their benefits some but not all of the time. The VA's supervised direct payment option for individuals who are determined to be incompetent but able to manage benefits with supervision

provides a model for such an approach. Instead of the VA's appointing a fiduciary for such individuals, they receive their benefits directly but under the supervision of a Veterans Service Center Manager. This approach could provide a model for a demonstration project by SSA.

Program Evaluation

Data are limited on the effectiveness of current SSA processes for identifying beneficiaries who should be evaluated for capability and on the accuracy of capability determinations among those identified for evaluation. Reports issued by OIG-SSA in 2004, 2010, and 2012 suggest that SSA's current capability determination process fails to identify all beneficiaries who would benefit from the appointment of a representative payee. The Committee made a number of recommendations that could increase identification of beneficiaries in need of a representative payee. Without baseline data and ongoing data collection, however, the effectiveness of current policies and the impact of the recommended changes cannot be evaluated. The committee therefore recommended that: **"The U.S. Social Security Administration should develop and implement an ongoing measurement and evaluation process to quantify and track the accuracy of capability determinations and to inform and improve its policies and procedures for identifying beneficiaries who are incapable of managing or directing the management of their benefits.**"

The measurement and evaluation process envisioned in the report would need to be designed and carried out by trained experts (whether in house or external) with detailed knowledge of SSA work flow and procedures. Such a process could comprise a variety of steps, including assessments of the interrater reliability of the capability determination process, indepth assessments of selected beneficiaries to determine the accuracy of earlier determinations, and evaluations of the impact of the Committee's recommendations in this report. A robust

measurement and evaluation process would provide substantial and much-needed insight into what SSA is currently doing well and what it may, at reasonable cost, be able to do significantly better.

Conclusions

Findings of incapability to manage SSA benefits and appointment of representative payees can be enormously helpful—even lifesaving—for beneficiaries who are truly unable to manage their benefits to meet their basic needs. But taking away the right to determine how one's funds are spent is a substantial intrusion on a person's autonomy and should be done only on the firmest of evidence. Alternatively, people without representative payees who need them remain vulnerable to undue influence and may not be meeting their basic needs. Hence, there are good reasons for SSA to develop as accurate a process as possible to identify beneficiaries who need a representative payee. Fortunately, there appear to be some fairly straightforward steps that could improve the current process, better protecting both the rights and interests of Social Security beneficiaries.¹

¹ A summary and additional perspectives on the report by several members of the committee is available here: <u>https://www.ncbi.nlm.nih.gov/pubmed/27363351</u>.