

Social Security Administration
Compassionate Allowance Outreach Hearing on Cancers
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Testimony of Thomas Yates
Compassionate Allowance Outreach Hearing on Cancers
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Thank you for the opportunity to testify concerning the Compassionate Allowances initiative. My name is Thomas Yates and I am an attorney with Health & Disability Advocates, a nonprofit agency in Chicago, Illinois. HDA staff work on many different levels to support and expand the safety net of benefits for low-income seniors and persons with disabilities, including children. HDA staff members represent individuals in legal matters, pursue class action litigation in appropriate instances, advocate on public benefits issues with administrative agencies at the state and federal levels, work on legislative initiatives, and provide consulting and training services to states on Medicaid, Medicare, and return-to-work issues. As part of HDA's work, three attorneys, including myself, have represented thousands of individuals—both adults and children—seeking Social Security Disability Insurance and Supplemental Security Income disability benefits. The majority of our clients are low-income, most are uninsured, many are homeless, and few have stable medical treatment.

Social Security claimants who are uninsured have a more difficult time navigating the Social Security disability process. First, most of our clients do not have continuity of medical care. They often cannot identify a doctor who has seen them over time. Many are treated at public hospitals, particularly Stroger Hospital (formerly Cook County Hospital), and free medical clinics where they do not see the same doctor from visit to visit. While these centers provide good health care, their patients often do not have ongoing relationships with doctors--they see the doctor who is available on their appointment days. As such, it is often impossible to identify a medical source that can assess whether medical listings are met and document loss of work-related function.

Second, because our clients do not have continuity of medical care, they often do not receive care in a timely manner. Sometimes, the delays are caused by staff and

funding shortages at public hospitals and clinics; patients often wait longer to receive appointments with specialists and to receive diagnostic testing. Other times, patients delay care because they are confused or are unable to navigate the medical care system.

Evaluation of Cancer Cases

Disability claimants with cancers that unquestionably qualify under SSA's Listings of Impairments have differing experiences in qualifying for Social Security disability benefits. At the BDDS level, if a) the claimant's records are available for review by BDDS staff, b) if those records contain the information needed to satisfy the relevant listing, and c) if there is no issue about duration of impairment, then Social Security decision-makers are usually able to make quick decisions, particularly at the BDDS level. However, even when all these factors are present, decision-making at the ODAR level can be delayed because of staffing issues. ODARs in the Chicago region are so overwhelmed with cases, including much older cases transferred in from other states, that decision-making on strong cases are still delayed. Even with the new Attorney Advisor initiative that allows attorney advisors to issue fully favorable decisions, I have seen delays because of caseloads.

However, if any of the factors set forth above are absent, then BDDS decision-making is delayed and claims are denied. First and foremost, there are still many problems in obtaining medical evidence. We see the following problems on a regular basis:

- a) some hospitals and doctor's offices do not provide information in a timely manner and the information provided is often incomplete;
- b) there is often confusion when getting records from doctors associated with hospitals; requests to doctors are ignored or returned with instructions to follow up with the hospitals for the same records even when the hospitals do not have control of the doctor's treatment records;
- c) some hospitals will not release records on a patient who is currently hospitalized; they will only release records after the claimant is discharged;
- d) certain medical providers will only release records if the date on the medical release is later than the dated of treatment;
- e) many hospitals have their own release forms and will only release records if their form is used;
- f) records from VA Medical Centers often do not contain sufficient information to determine disability status;
- g) most medical providers charge copying and mailing charges for records; in Illinois, bills of \$50-\$100 are common for hospitalization reports; and
- h) medical records departments scrutinize requests and reject many proper requests because of fears of HIPAA non-compliance.

Second, we see problems because of a disconnect between information needed to show disability under the Social Security disability definition and the types of

information usually provided by medical providers. The major problem that we encounter is obtaining additional information when the medical records provided are insufficient to satisfy the disability standard. Doctors often do not have time to return calls from attorneys. Even when we can talk with treating doctors, it takes time to explain what information we need from them for Social Security purposes. Doctors also do not have time to draft statements specific to the client and his or her ability to sustain work with their medical impairments. Because of this, we rely on nurses and social workers whenever possible to get access to medical records and request statements from treating doctors. We also ask clients to take forms to their doctors at scheduled appointments and to stress to their doctors the importance of the information provided by treating doctors. My understanding is that Illinois' BDDS adjudicators have these problems as well.

Another aspect of this disconnect is that doctors, particularly specialists, do not always consider their patients' ability to function in a broader sense. In my experience, the cancer surgeon considers the result good if the surgery went well. However, that doctor often has no information about the patient's day-to-day functioning with the sequelae of radiation therapy, chemotherapy or other cancer treatments. Often the oncologist is no better. In such cases, the primary doctor may have a better idea of how able the patient is to sustain work activity. And, finally, in some cases, none of the doctors have a comprehensive understanding of how the patient is doing and that patient's ability to do work-related function. Thus, reliance on medical sources that lack comprehensive information about the patient's day-to-day functioning leads to failures to consider the effects of cancer therapy as well as all other medical impairments. In such cases, decision-makers need to develop and consider credible lay evidence, from the claimant or from the claimant's family or friends. This failure to develop comprehensive evidence about functional deficits also results in durational denials when decision-makers do not factor the effects of treatment into duration of the impairment.

And, in many cases, other medical impairments, considered in combination with cancer can support a finding of disability. For example, I often see cancer cases in which depression or another mental impairment is present. However, evidence of depression or other mental impairment has not been developed—treatment records may not have been obtained and the impact of that impairment on the ability to sustain work has not been developed.

Third, the duration requirement contained in the statutory definition of disability (disability caused by impairment that is expected to result in death or that has lasted or is expected to last for twelve months) also causes delays. The listings note that in cancer cases in which there are no distant metastases, the decision-maker must wait to see the claimant's response to treatment regimens. See 20 C.F.R. Part 404, Subpt. P, § 12.00E.2. Because of this, decisions are often held for several months to assess the effectiveness of treatment.

However, the listings also provide that “we do not need to defer adjudication to determine whether the therapy will achieve its intended effect if we can make a fully favorable determination or decision based on the length and effects of therapy, or the

residuals of the malignancy or therapy (see 13.00G).” See 20 C.F.R. Part 404, Subpt. P, § 12.00E.3. I believe that Social Security decision-makers can do more at this step to determine whether the claimant meets the disability standard. Often, as discussed above, state BDDS’s will not ask about the effects of therapy set forth in § 13.00G, 20 C.F.R. Part 404, Subpt. P, App. 1.

TERI, QDD, and Presumptive Disability

SSA has processes in place designed to expedite the disability determination process. Two—TERI and the recently-started Quick Disability Determination process focus on adjudicating cases quickly. I do not have much experience with TERI cases at the BDDS level. My sense, however, is that adjudicators have full caseloads and, because of that, they have difficulty focusing on a single case for adjudication purposes because of the demands of other cases in their caseload. At the ODAR level, because of overwhelming caseloads, my sense is that the TERI process does not work efficiently.

However, my understanding of how the Illinois BDDS handles QDD cases addresses caseload issues. My understanding is that QDD adjudicators have time to focus on individual cases and to do intensive phone work to acquire needed evidence to document disability in strong cases, including cancer cases. They rely on nurses or social workers to help obtain medical records and involve the family in assisting to obtain relevant records in some cases. Because of this, they are able to adjudicate cases quickly. However, it appears that the number of cases that are eligible for QDD consideration are limited. My understanding is that claimants who do not have a treating source are not eligible for QDD consideration. This excludes, for example, claimants who are uninsured who are less likely to have a treating source.

Presumptive eligibility is applicable in limited numbers of cancer cases, usually when the claimant has less than six months to live. In my opinion, the most useful feature of presumptive disability is that it entitles claimants to Medicaid eligibility. For persons who were uninsured, Medicaid eligibility allows them to access medical care, and those treatment records often provide proof of disability. The major problem with presumptive disability is that it is limited to six months, regardless of how long BDDS takes to make the initial determination. For example, BDDS could defer adjudication of a cancer claim to assess the effectiveness of therapy longer than six months. Presumptive disability should continue as long as the initial decision process takes.

Improving the System for Persons with Cancer

Ensuring that persons diagnosed with cancer have access to medical care would be the most helpful. First, it would give these individuals a greater chance of surviving their cancer and returning to productive lives. Second, having Medicaid coverage, for example, would allow them to receive greater continuity of care and open the range of options for care that is available. Providing presumptive disability status to claimants with diagnosed cancer would allow them to qualify for Medicaid coverage.

Second, I believe that adjudicators and other Social Security decision-makers would benefit from information that describes the impact and functional limitations that may result from different cancers would be helpful. Such information would assist decision-makers in assessing functional limitations in cases in which the evidence does not support a finding that the cancer meets the medical criteria of the appropriate listing.

Third, Social Security decision-makers should ask treating doctors to assess their patients under the relevant listings. A patient's doctor should be provided with the specific listing language and asked for his or her opinion on whether the medical evidence satisfies the listing.

Fourth, treating doctors should be asked to assess the effects of therapy, described in § 13.00G, 20 C.F.R. Part 404, Subpt. P, App. 1.

Fifth, treating medical sources who have knowledge of their patients' functional limitations should also be asked to rate their patients' ability to sustain different work-related functions, i.e. how long could your patient be expected to stand during a normal day or how much could your patient lift? Currently, Social Security decision-makers do not ask treating doctors to evaluate functional limitations. That practice should change. And, as discussed above, if the specialists do not have this information, then decision-makers have to obtain that information from primary doctors, or from the claimant and his or her family or friends.

Sixth, the QDD project should be expanded to greater numbers of cases and BDDS staff should be allowed to refer appropriate cases to the QDD process for adjudication even though they were not picked up by the predictive model. SSA should also explain to advocates which cases are subject to QDD review so that we can refer appropriate cases.

Seventh, Social Security must not forget about delays in the payment process. Often, claimants who are found disabled will wait for months to receive their benefits. Cases involving cancers that are found to meet the disability standard need should have the payment process expedited.

Finally, in closing, SSA must not forget that making disability determinations requires trained staff with experience in reviewing cases. While development of the electronic file and expected advances in electronic medical records will aid disability decision-making, they will not obviate the need for Social Security staff. I believe that current staffing levels at all levels of SSA are insufficient to handle current caseloads.

Thank you for the opportunity to provide my thoughts.