
DLC

Disability Law Center, Inc.
11 Beacon Street, Suite 925
Boston, Massachusetts 02108
(617) 723-8455 *Voice*
(800) 872-9992 *Voice*
(617) 227-9464 *TTY*
(800) 381-0577 *TTY*
(617) 723-9125 *Fax*

Western Mass Office
30 Industrial Drive East
Northampton, MA 01060
(413) 584-6337
(800) 222-5619
(413) 582-6919 *TTY*
(413) 584-2976 *Fax*

<http://www.dlc-ma.org>
email: mail@dlc-ma.org

Testimony of Linda Landry, Disability Law Center
Compassionate Allowance Outreach Hearing for Rare Diseases
Social Security Administration
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I thank the Commissioner for this opportunity to testify on the topic of improving disability determinations for rare diseases and conditions. I am a senior attorney at the Disability Benefits Project at the Disability Law Center, where I have practiced since 1990. The Disability Benefits Project is a backup center for legal services advocates who represent individuals before the Social Security Administration. From 1980 to 1990, I worked as a staff attorney at Neighborhood Legal Services in Lynn, Mass., where I provided representation on the full range of public benefits. In both positions, I have represented individuals and participated in systemic advocacy.

It is my experience that the problems with the disability determinations for rare conditions are generally the same as those for more common conditions. Applications are denied that should have been allowed earlier for many reasons, including the following.

- * Not all conditions and/or sources of evidence are identified up front. Many applicants have difficulty completing the application and associated forms in sufficient detail. They may not know the precise names of their conditions, may have difficulty describing the effects of their conditions, and may not know that they should include all their conditions and diseases on the application. In addition, the application and associated forms focus on identifying doctors and hospitals as medical information sources. Yet, other professionals are often important sources of information on the nature and severity of impairments. These sources often have more information than the applicant's doctors on how the individual functions on a day to day basis with his or her impairments. Obtaining this information is frequently necessary to correctly analyze the nature and severity of an applicant's impairments.
- * Doctors and other providers are not asked for all the information SSA needs. Standardized

forms seem to exist for some for specific impairments but not all. Sometimes the existing forms are out of date. Doctors and other providers seldom understand SSA's disability standard and do not know what information SSA needs to analyze a disability case. In addition, there is insufficient recognition at SSA that medical records show doctors and other providers communicating to each other in ways they understand but which may lead to misunderstandings by outsiders. For example, a note that the patient is "doing well" may mean "well under the circumstances", and, "moderate" in describing a condition or symptom may mean something fairly severe on the scale on which the impairment is measured. Follow up with the provider to clarify information should occur (20 C.F.R. sections 404.1527(b), 416.927(b)) but often does not.

- * Functional capacity information is not sought from treating sources and other sources that work with the applicant. This information is often crucial to a complete analysis of an application but is not sought from those with first hand knowledge of the applicant's ability to function in light of his or her impairments.
- * Medical providers often lack staff to make a quick response to information requests. This is especially true of busy clinics and hospitals that serve low-income communities. They struggle to keep sufficient medical staff to serve their patients and may not lushly staff the medical records department or have the latest electronic equipment. In addition, privacy laws and concerns may result in delay in obtaining medical and other evidence. For example, scrutiny of medical releases under HIPAA and staff misunderstandings about HIPAA result in delay. It often takes many follow up requests to obtain medical records from providers and the disability determination often moves ahead without it.
- * Medical expertise available to SSA's adjudicators is often inadequate. This may be due to in part to the reimbursement available for hiring medical expertise. Where medical expertise is not available for rare or newly identified conditions and diseases, they may be treated with suspicion when efforts should be made to communicate with treating providers and specialists to learn about the conditions. For example, I have seen this problem with lupus, chronic fatigue syndrome, HIV and AIDS, reflex sympathetic dystrophy, and metabolic disorders over the years.
- * Disability evaluation rules are not always followed. Often misapplied are the rules concerning: what evidence can be considered to evaluate functional capacity (20 C.F.R. sections 404.1513, 416.913); the weighing of opinion evidence (20 C.F.R. sections 404.1527, 416.927); the evaluation of pain and other subjective symptoms (20 C.F.R. sections 404.1529, 416.929); and the evaluation of mental impairments, (20 C.F.R. sections 401.1520a, 416.920a, Part 404, Subpart P, app1, section 12.00).
- * Existing expediting processes are not always applied to expedite the disability determination and do not necessarily work to expedite payment. Currently, there seems to be some confusion as to whether QDD has supplanted TERI flagging and the Presumptive Disability processes. There will always be a need for TERI flagging, even with QDD. And Presumptive Disability (PD) is valuable because it can result in up to six months of presumptive payments while the disability determination moves formally

forward. District Offices can make a PD finding for only a limited list of impairments. The Disability Determination Services, however, can make a PD finding whenever the evidence indicates a high degree of probability that the applicant will be found to meet the disability standard. 20 C.F.R. section 416.933. PD is, unfortunately, limited to initial disability determinations in SSI cases.

In short, a substantial amount of needed improvements to expedite disability determinations for rare diseases and conditions would benefit most disability cases. The following improvements should be considered to improve information gathering for faster and more accurate decision-making.

- * Collect contact information for non-MD medical sources, and other professional sources, as well as MD sources.
- * Provide applicants with more help completing application paperwork so that all impairments and sources of information are identified. Provide applicants with information about the type of evidence needed for the disability standard.
- * Update and improve the forms sent to doctors and other sources of evidence to specifically request necessary information. Emphasize the need to contact these sources for clarification to ensure that information is not misconstrued and that decisions are not made on apparent inconsistencies that are not actual inconsistencies.
- * Collect functional capacity information from sources who have seen/evaluated the applicant earlier on in the process.
- * Improve the medical expertise available to adjudicators by increasing reimbursement and expanding the range of expertise available for in house use by the Disability Determination Services, for consultative examinations, for quality review, and for Medical Experts at hearings.
- * Provide more training/guidance to adjudicators on important evaluation rules, such as the treating source weighing rules, the role of non-physician evidence, and the evaluation of mental impairments, pain, and other subjective symptoms.
- * Provide more training/guidance on the evaluation rules for childhood disability. Many SSA evaluators and adjudicators still do not adequately understand how to evaluate a child's disability under the childhood disability standard. This leads to unnecessary denials in child disability cases.
- * Provide training on use of the Social Security Rulings. Many of these rulings provide very useful guidance in various areas of disability evaluation and are easily accessed on SSA's website. Those on specific, little understood impairments have been very useful, e.g., SSR 85-15 (includes instructions for evaluating functional capacity in claims involving mental impairments), SSR 99-2p (evaluating Chronic Fatigue Syndrome), SSR 02-2p (evaluating Interstitial Cystitis), SSR 03-2p (evaluating Reflex Sympathetic Dystrophy). In addition,

SSR 06-3p explains the types of evidence that must be used to establish medically determinable impairments and the types of evidence that can be considered to evaluate the nature and severity of the impairment. These rulings are underused.

- * Improve use of the existing methods of expediting disability determinations.
 - * Clarify that QDD does not supplant TERI (Terminal Illness) flags and Presumptive Disability (PD) evaluations.
 - * Make sure that TERI flagging works as you move into electronic folders and that TERI flagging also expedites payment.
 - * Consider creating something like PD for use beyond SSI initial level evaluations.
 - * Allow/require adjudicators at all levels to screen for and to make a PD finding or a fully favorable on the record (OTR) finding whenever the evidence or case analysis merits such a finding.
 - * Expedite payment proceedings for PD and fully favorable on the record (OTR) cases.
 - * Consider expanding the guidance on PD to ensure inclusion of more rare diseases and terminal/grave condition cases. The guidance could include a non-inclusive list of conditions that should be considered for PD. This list could also be used for other types of screening. However, any such list would need to be updated regularly. It would also be critical to be very clear that any such list is not all inclusive to avoid denigrating consideration of conditions and diseases not on the list.
 - * Screening for possible TERI, PD, and/or OTRs should occur earlier in the process and be ongoing.
 - * Among conditions that should be included in screening are, but are not limited to: metastatic cancers, people with high VA disability ratings, cystic fibrosis, down syndrome, cerebral palsy with quadriplegia, muscular dystrophy, statutory or legal blindness, severe, chronic mental impairments, including those that would meet part C of the listings; severe metabolic disorders, Fragile X, Fetal Alcohol syndrome, Rett Syndrome, other severe congenital disorders, people with severe burns.