

**An Exploratory Study to Assess the Evaluation of Chronic Pain in the Social Security Administration Disability Determination Process<sup>1\*</sup>*****Phase II: Investigating Institutional Interaction between Legal, State, and Medical Institutions*****Abstract**

This study is the second phase of a two-part study to analyze how chronic pain is evaluated comprehensively across institutions in the Social Security Administration (SSA) Disability Determination Process (DDP). Chronic pain is noted as one of the most problematic areas of disability determination. Those who seek disability benefits on account for their chronic pain have among the lowest initial allowance rates yet the highest reversal rates in the appeals process. Medical uncertainty and cultural bias about the subjectivity of pain has manifested in conflicting changes in SSA, legal and Congressional rulings on the evaluation of chronic pain, and resulted in inconsistent implementation from medical adjudicators across DDP institutions. Though recent Social Security Rulings on the evaluation of symptoms (including pain) have provided more detailed and inclusive factors to consider in evaluation, this adds to the complexity of decision-making. This study seeks to improve methods for efficient and reliable complex decision-making in the evaluation of chronic pain. Phase I analyzed interview data from claimants, treating physicians, and Consultative Examiners, and highlighted specific problem areas in the evaluation of chronic pain in medical and state institutions. Phase II investigates legal institutional processes of disability evaluation through interviews with legal representatives, judicial clerks, Administrative Law Judges, and a Disability Examiner. The discussion and recommendation sections integrate findings across both phases to provide comprehensive analysis.

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## Introduction

Chronic pain is one of the most problematic areas for disability determination in Social Security. Bierman (1998) notes that “the subjective nature of pain allegations makes them substantially daunting to assess”, which leads to “pain evaluation determinations [being] involved in almost half of the Social Security disability cases pending in the federal court system; such determinations have been noted as the most problematic area in Social Security law.” Social Security Rulings (SSR), legal and Congressional rulings have attempted to create standardized rules for the evaluation of chronic pain in the Disability Determination Process (DDP); but to date these regulations are unclear, and ongoing court cases demonstrate a high level of inconsistency in adjudication, institutional inability and/or “nonacquiescence” with regulations (Rogers 1991; Masson 1994; Purvis 2011).

Due to these issues, in 1984, Congress created the first standardized definition for how pain should be evaluated in the DDP. They also mandated that a commission be created to better understand the issue of chronic pain and make recommendations. The resulting Institutes of Medicine (IOM) 1987 noted: “the study committee was struck by the complexity of the disability system and by the extraordinary complexity and multifaceted nature of chronic pain”, and determined that:

Human judgment and subjectivity are inherent in [the pain evaluation] process and appropriate to determinations that require a combination of so many different kinds of information—medical, psychosocial, functional, and vocational...the real issue should not be how to eliminate subjectivity from the assessment process, but how to factor subjective elements into the determination process in a more reliable and valid manner.

This researcher’s study advances the IOM report using a qualitative, in-depth approach to achieve the goal of reliable complex decision-making in the evaluation of chronic pain. The current study is the second phase of a two-part study that analyzes how chronic pain is evaluated in the Disability Determination Process (DDP). The first phase of the study analyzed interview data from claimants, treating physicians, and Consultative Examiners (CEs), and highlighted specific problem areas in the evaluation of chronic pain in medical and state institutions. Findings also pointed to the centrality of legal institutions in the DDP for chronic pain claimants, as all but two claimants were denied disability at initial and reconsideration levels, and out of the remaining ten, four are awaiting their hearing, and six were awarded disability by the Administrative Law Judge (ALJ) in their disability hearing. These findings parallel both legal literature and SSA statistics, which show that chronic pain conditions have among the *lowest* initial and reconsideration allowance rates, but the *highest* reversal rates in ALJ appeals (IOM 1987; Sanbar 2010; Meseguer 2013). Thus, phase II of my study investigates disability evaluation within the legal institution in order to develop a more comprehensive understanding of disability determination across institutions.

The findings presented in this report come from 24 semi-structured, in-depth interviews with legal actors in the DDP (thirteen legal advocates, two clerks, and eight ALJs) and one Disability Examiner (DE) from the SSA. This qualitative methodology was chosen because long-form, in-depth interviews yield close insight into “the often hidden interactions of cultural attitudes, institutional processes, public policies, and individual lives...to shed light on the complex interrelationships among physical impairment, societal barriers, and public programs” (O’Day

and Killeen 2002). In the findings section, I provide data from phase II that elucidates legal institutional processes in the evaluation of chronic pain in the DDP. I also provide data on ALJ attributions for why there exists large variation between state and legal decisions on chronic pain, as well as variation across ALJs. In the discussion section, I integrate findings from both studies—across 44 interviews with claimants, CEs, a DE, and legal actors in the DDP—to identify six issues to be resolved for consistent and reliable evaluation of chronic pain across the DDP. I then provide recommendations to resolve these issues.

## Summary

### Phase II Findings:

Large variation between DDS and ALJ decisions on chronic pain claims stems from four factors:

1. Legal representatives providing records, evidence, and information
2. ALJ/court attorney training and experience
3. Being in-person with claimants
4. Claimants getting sicker over time

Large variation between ALJ decisions stems from three factors:

1. Personal biases
2. Inconsistent training
3. The nature of subjective ‘gestalt’ decision-making

### Phase I and II Comprehensive Analysis:

Six issues to be resolved for efficient and reliable evaluation of chronic pain:

1. Lack of access to information, medical records, and adequate evidence
2. Volume pressure and incentivization to process cases quickly
3. Bias and discrimination based on pain, evidence and diagnosis
4. Insufficient specificity for complex decision-making
5. Inconsistent and insufficient training
6. Lack of feedback mechanisms in the SSA

Policy recommendations:

1. Establish ‘complex symptomatology’ as category of claimant (internally)
2. Provide targeted resources for this population
3. Develop specific guidelines and decision support for complex decision-making
4. Provide consistent and continuing education trainings
5. Assess decision-making bias
6. Provide feedback mechanisms in the SSA
7. Hire more adjudicators and support staff<sup>2</sup>

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<sup>2</sup> It is hoped that recommendations 1-6 will help alleviate high caseloads and volume pressure on adjudicators in lieu of the fact that hiring more staff incurs costs to the SSA—an option not always available due to agency funding levels and in the context of a shrinking operating budget. Adverse effects of budgetary-induced staff cuts on record-high workloads with fewer resources have been noted (Romig 2016; SSA FY 2017 Fiscal Budget Overview), and it is hoped that this study further clarifies the costs of high caseloads and volume pressure in support of SSA requests for the necessary funds to cover staffing (SSA FY 2017 Fiscal Budget Overview)

## Literature Review

Medical technologies for substantiating and diagnosing pain are underdeveloped in the medical field. AMA Guides to the Evaluation of Impairment states that “[a]t least 10% of all medical-surgical patients have no objective evidence of disease. The absence of a diagnosable disease does not mean the absence of abnormalities, disturbances, or alterations in bodily functions. Thus, severe illness, illness behavior, and suffering can exist in the absence of a diagnosable disease” (citation in Agatstein 1997). Many patients complain of pain in multiple, seemingly unrelated places in the body, or as ‘radiating’ throughout the body, which has eluded understanding in medical science for much of the 20<sup>th</sup> century (IOM 1987). However, though diagnostic techniques remain limited, medical models of pain post-1970s are highly sophisticated and can explain connections between pain and abnormalities in neurological, immune, and psychological systems that can result in complex pain responses in patients (DeLeo 2006; Gatchel et al. 2007). These medical models stimulated the creation of “idiopathic” diagnoses like fibromyalgia and complex regional pain syndrome—both of which now have specific Rulings for decision-making in SSA determinations. Despite the existence of sophisticated medical models of pain, these models are not widely disseminated across medical disciplines, pain remains a very small section of medical education, and the poor treatment of pain is one of the current largest health crises (Tellier et al. 2013; Loeser and Schatman 2017). Additionally, there exists extensive cultural and medical skepticism about the credibility of patients alleging pain—especially pertaining to biases about race, class, ethnicity, and gender (Trawalter et al. 2012; Wailoo 2014; Berkowitz 2015; 2016; Pryma 2017).

As background, in the DDP, disability claims are first evaluated by the Disability Determination Service (DDS)—Social Security’s state agency—in an initial decision, and in most states, a reconsideration stage. If denied, the claim goes to a hearing in front of an Administrative Law Judge. Denied ALJ claims are reviewed by an SSA-appointed Appeals Council of judges, and then may be appealed to the state or federal judiciary. Just as with healthcare, medical uncertainty and cultural bias about the subjectivity of pain has manifested in conflicting changes in SSA, legal and Congressional rulings, as well as inconsistent implementation from medical adjudicators across DDP institutions (IOM 1987; Rogers 1991; Agatstein 1997; Bierman 1998; Purvis 2011). Socio-legal research and court cases substantiate that biases of SSA adjudicators about the credibility of claimants alleging pain—especially along the lines of race, class, ethnicity, and gender—have influenced adjudicators decisions (Finch 2005; Purvis 2011; Berkowitz 2016; Pryma 2017). Strikingly, legal literature and SSA statistics show that chronic pain conditions have among the *lowest* initial and reconsideration allowance rates at the DDS level, but the *highest* reversal rates in ALJ appeals (IOM Report 1987; Sanbar 2010; Meseguer 2013).

There are several key reasons for such differentials: first, cases arriving before ALJs are frequently incomplete, and are then developed through requests of ALJs to physicians (IOM Report 1987). Thus, ALJs have more information to go off of in decision-making. Second, long wait times between DDS decisions and court appearances often manifest in claimants’ condition worsening. Third, the nature of court appearances being in-person versus DDS decisions in absence of face-to-face encounters with claimants (ibid). Fourth, rulings in state and legal institutions can be in opposition, and judges can be in conflicting position between SSRs and

legal standards. Standards can vary within the legal institution as well (Rogers 1991; Agatstein 1997; Bierman 1998; Purvis 2011).

Past case law and judicial standards have both instantiated the use of subjective claims of pain as evidence in and of itself, or stated that subjective claims should only be considered if objective medical evidence is found to substantiate the claim. However, according to the SSA Ruling, chronic pain can only be a *symptom* that must be part of another “medically determinable impairment” recognized in the “Listing” of disabling conditions. Subjective testimony is considered only if “objective medical evidence from an acceptable medical source [establishes] the existence of a medically determinable impairment that could reasonably be expected to produce an individual’s alleged symptoms” (*SSR 16-3p*). Still, litigation alleging SSA bias for objective evidence and against subjective testimony has resulted in successful outcomes for claimants against the state. In one 8<sup>th</sup> circuit court case, the SSA “conceded” that “some adjudicators may have misinterpreted” Rulings and rejected pain disability claims without consideration of subjective testimony of claimants (Masson 1994). There is also some evidence that Consultative Examiners (CEs)—physicians hired by the SSA to do in-person examinations of claimants when sufficient evidence is felt to be unavailable or inconsistent—also solely consider objective evidence in their examinations of pain claimants (Berkowitz 2016).

Compounding this problem, the SSA follows a unique and heavily criticized “policy of nonacquiescence” that allows federal agencies such as the SSA to “refus[e] to be bound by federal court decisions beyond the case of the particular litigant” (Masson 1994). This means that many individual or class action claims have to be filed against the SSA, rather than establishing the case as binding precedent as is done in law otherwise. A Congressional ruling or Supreme Court decision are the only ways for the SSA to change its policies at a systematic level when such dissention occurs. Partially in response to the issue of pain, Congress passed the Social Security Disability Benefits Reform Act in 1984, which the current SSA Ruling reflects, and a mandate for further investigation of the pain issue. Two commissions and reports resulted: the Health and Human Service’ *Report of the Commission on the Evaluation of Pain* (1986) and the Institutes of Medicine’s *Pain and Disability* (1987). Neither commission felt that clear recommendations could be made without more research due to the complexity of the pain issue.

The IOM report did provide rich detail on the complexity of pain, which are reflected in latter Rulings for adjudicators to include in their consideration (Agatstein 1997). The current Ruling, *SSR 16-3p*, stipulates that adjudicators must make decisions based on a comprehensive consideration of a multiplicity of factors; for instance, factors that precipitate symptoms, and non-medical measures claimants may use to alleviate pain (e.g. lying on one’s side). It includes a number of caveats for why certain indicators may not be utilized; for instance, one important factor considered is: “an individual’s attempts to seek medical treatment for symptoms and to follow treatment once it is prescribed”, followed by a caveat negating its possible relevance in the case that “an individual may not be able to afford treatment” or that “a medical source may have advised the individual that there is no further effective treatment to prescribe”. While this Ruling is a more detailed, balanced, and inclusive Ruling for pain evaluation, it also adds complexity to determination without clarity for *how* to evaluate the many factors it includes in conjunction with one another. In addition, many of the factors to be considered are based on subjective reporting, which are more subject to the biases noted above (Stone 1984; IOM 1987).

In sum, the 1987 IOM report concluded that:

Human judgment and subjectivity are inherent in [the pain evaluation] process and appropriate to determinations that require a combination of so many different kinds of information—medical, psychosocial, functional, and vocational...the real issue should not be how to eliminate subjectivity from the assessment process, but how to factor subjective elements into the determination process in a more reliable and valid manner.

Though the current Ruling takes into account these complex factors, it does not resolve the problem of how to evaluate these factors in a more reliable manner. Thus, this study addresses the goal of improving methods for reliable complex decision-making in the evaluation of chronic pain. Phase I of the study addressed the medical and state components of the DDP, and phase II addresses the legal component.

### **Methods**

*Recruitment:* First, legal representatives were recruited from claimants in phase I of the study. Both claimants and I called and emailed recruitment texts to claimants' legal representatives, and representatives also gave our recruitment material to representatives in their networks. Further recruitment of legal advocates was done using FindLaw.com, using "Social Security Disability" as the legal issue and California as the location, and legal representatives also gave our recruitment material to representatives in their networks. To recruit ALJs, a recruitment email was sent out via the National Association of Administrative Law Judiciary to all members, and ALJs also gave our recruitment material to ALJs in their networks. A second population of ALJs was recruited by emailing recruitment scripts to ALJs' official email addresses. Recruitment for ALJs had to be curtailed after two months due to the SSA withdrawing their support for ALJ participation in this study.

*Interviews:* We conducted 24 semi-structured, in-depth interviews with legal actors in the DDP [thirteen legal representatives, two clerks, and eight ALJs and one Disability Examiner (DE)]. Interviews with advocates focused on their role in the DDP and their experiences with and views on actors in other parts of the DDP. Interviews with ALJs focused on how they evaluate claimants with chronic pain, and their experiences with and views on actors in other parts of the DDP. We solicited feedback on future improvements to the SSA/DDP from all participants.

*Analysis:* To analyze interview data, I created inductive codes in Atlas.ti based on questions asked to each population. I triangulated data between the populations in order to verify consistency of my findings across the different populations of the study. I then inductively grouped shared thematic codes into a set of issues addressed at the purpose of this report: to identify issues to be resolved for efficient and reliable methods for evaluating chronic pain. I then compared these issues to those identified in phase I of this study, and developed a set of recommendations that addressed findings of both studies.

### **Sample**

The research sample consisted of one DE, thirteen legal advocates, two judicial clerks, and eight ALJs. Legal representatives consist of twelve attorneys and one advocate (a representative sans

law degree). Representatives' legal practices range widely between large firms, small or lone private practices. All have been in practice for at least five years, and a majority practice in California. Judicial clerks formerly clerked for federal magistrate judges in two different states, where their job was to determine whether ALJ decisions were valid or necessitated a remand. Both clerks state that the judges they clerked for almost always signed off on clerks' decisions without reading them (also citing this as common practice across judges). ALJs were a majority retired judges, all of whom had served as court attorneys prior to becoming ALJs. All had practiced in multiple US states, a majority including California. The DE has worked for the SSA doing disability evaluations for seven years at both DDS and federal levels.

## Findings

### *Legal Institutional Processes for Chronic Pain Evaluation in the DDP*

#### *The Roles of Legal Representatives*

Legal representatives have seven major roles in the DDP: **1)** Screening claimants; **2)** Gathering and updating medical records; **3)** Identifying outstanding evidence needed; **4)** Advocating for the claimant to physicians; **5)** Educating claimants, physicians, and ALJs; **6)** Identifying important parts of the medical record for the judge; **7)** Constructing an argument for why the claimant is disabled. Though most of these roles are common to representation for all disability claimants, they take on specific importance in claims of those with chronic pain.

Most legal representatives come into the DDP after claimants have been denied at the initial and reconsideration levels of the DDS. Only two attorneys say that they will get involved before the legal level either because of financial incentives not to, or because they used to take on cases at the initial level, but that even with their help and sufficient evidence according to SSA Rulings, cases were still denied at the DDS level. Representatives comment that according to legislation, they only get paid if they win cases, and are paid on the past-due benefits that result from the favorable decision. Hence, they are financially incentivized to help claimants after cases have been pending in the DDP for a long time.

Legal representatives first determine which claimants have a case with a chance of being successful. Representatives take phone calls with claimants to understand their case, and they may screen out cases that only have subjective complaints of pain and do not comply with the SSA mandate for a Medically Determinable Impairment. Some will also try to assess the credibility of claimants who may not have such evidence, in order to determine whether working to get access to such evidence is worth it for taking on the case. Representatives will assess credibility by talking to the claimant and trying to get a "feel" for whether the person is telling the truth. Additionally, some screen out cases of poorer claimants, as these claimants may not have access to needed evidence even with representatives' help; however, a majority will work to get such evidence regardless.

Many representatives lament how much of their role is just doing legwork that the Disability Determination Services (DDS)—Social Security's state agency that actually determines claims—should do earlier in the process: getting claimants' medical records and obtaining outstanding evidence. Both ALJs and representatives note that agents of the DDS do not complete this task a

majority of the time, leaving records incomplete. While this is a problem for all disability claims, it particularly harms claimants with chronic pain, whose cases often depend on a complex adjudication of multiple factors from the medical record.

Healthcare providers' non-compliance with DDS requests is the major reason for this lack of medical records. The Disability Examiner interviewed—the bureaucrats who handle claims at the DDS office—states that the DDS will make several requests to claimants' physicians, but then cases are processed without records after about 30 days. She confirms that many physicians and hospitals don't send them, and states that "of the 70% denials that the SSA does, probably in 60% of those cases, there are missing records". In lieu of this, representatives say that obtaining claimants' medical records often cannot be done passively through such mailed or phoned requests; rather, representatives will go to providers' offices to manually get records. Also like the DDS, representatives will identify further evidence needed to adjudicate the case; however, representatives state that they are more consistent in such requests and comprehensive in their knowledge of what should be requested than DDS employees. They identify that a Residual Functional Capacity (RFC) Assessment—a form provided by the SSA—and a providers' medical source statement is essential to winning cases. Representatives will also create forms they see as superior and more detailed than SSA-provided forms. Importantly, they use their knowledge of specific judges' biases and preferences to identify needed evidence or ways of presenting cases based on which judge is assigned to the case.

Representatives must often become advocates for their claimant to medical providers, as the advocate Leo<sup>3</sup> demonstrates:

[Doctors] say "well were treaters not paper-workers"...but they should be advocates for their patients and they're not for the most part...[they] try to push it away and then it involves the advocate keeping the thing and along with the client to jar that physician to meet what I think is his ethical obligation...the advocate has to almost lead him and say, "here's a Residual Functioning Capacity Assessment...how long can [the claimant] stand? How long can they walk? How long can they sit?"

The issue is also an institutional one, as certain medical organizations have policies against helping patients with the DDP, namely Kaiser and community health centers. Representatives say that both physicians and institutions may also charge large sums of money (\$160-300) to fill out information like the RFC. These issues highlight that poorer claimants suffer the most from these healthcare problematics. One attorney say that he will even front the money to a client to get imaging done if he feels it is central to their case, but that most of the time, poorer claimants just don't have the evidence needed to prove their pain.

Representatives also serve the role of educator to physicians. Frustration with the issues above led the attorney Samuel to become part of a disability advocate group called the Health Consumer Alliance, which does education through their website and physician trainings. He says:

We developed materials on documenting disability for clinicians. We meet with doctors and do trainings and explain to them [what] it's important to document...[otherwise] they approach their notes as in 'what do they need to write in order to bill for this'...some doctors will then do it and

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<sup>3</sup> all names are pseudonyms

some won't...it used to be that if there wasn't enough evidence or if there was a conflict in the medical record, Social Security was supposed to make "every reasonable effort" to get additional information from a treating source...[instead] they pay they pay these doctors, who are professional Consultative Examiners, to see patients once...and those exams are almost uniformly terrible...these exams can be five or ten minutes...so we spent years trying to get Social Security to ask the treating doctor...[but] they're so reluctant to do that so we do their job for them.

Representatives also educate claimants, for whom the process is especially difficult to understand given the complexity of chronic pain claims. Elliot notes that his clients "get letters from Social Security that, I'll tell you what, if you're not an attorney, you can't understand it...[claimants] call [Social Security] and sometimes get put on hold for hours...it's very frustrating, very demeaning". Several attorneys say that they also educate ALJs about medical evidence and about Rulings on cases pertaining to symptom-based diagnoses like chronic pain. Allison comments that "in the [chronic fatigue syndrome], fibromyalgia, and [complex regional pain syndrome] cases...even though the Rulings exist and they're issued by the Social Security Administration, I find that the judges are not always so familiar with them. Nor are the staff attorneys. So...we outline the Rulings step by step".

The last component of representatives' roles is preparing the case for the judge: identifying important parts of the medical record and constructing an argument for why the claimant is disabled. The complexity of chronic pain claims particularly necessitates such help, as Mariah explains:

There's usually about 800 pages of medical records...then I try to have a 6 to 8 page brief to say to the judge "there is method to the madness. There is some shape. There is some context here". Because generally...[clients] had maybe 3,4,5,6, some people 9 years of going around to different doctors. Negative x-ray, negative MRI, negative C-reactive protein, negative AMA, negative nerve conduction study, you name it...and then they get that positive antibody test to a neurologically involved infection. And so if the judge is just looking at the record, you know, it would be organized usually chronologically...by the time they get to a yes...we're all human, and even though we know intellectually it's not 'well twelve no's and one yes, the no's win', it's not a democracy. It's 'is there a laboratory finding that supports the claim?'...I tell them 'we're counting yes's'.

All representatives also mention that their knowledge of specific judges' biases for evidence and against certain diagnoses is central to arguing their case. Mark states that "depending on where you are and who your judge is, it may become very important to abandon the fibromyalgia discussion and focus on the other comorbidity." Representatives also feel that this bias is present at the DDS level, and the commentary of the interviewed Disability Examiner confirms this: "The fibromyalgia diagnostic criteria is that literally, nothing else is wrong. And they poke a few spots in your back and say "this hurts in 11 spots. I guess you have fibromyalgia". Evidence of this bias at the Administrative Law Judge level is presented in the next section. Hence, even though the SSA Ruling on fibromyalgia provides specific findings to be considered in determination, cultural biases can override these stipulations.

Representatives mention that specifically knowing how to argue against Consultative Examiner testimony is central, as all representatives question the quality of such exams for chronic pain cases. To do so, representatives will argue that the DDS did not provide CEs with medical records, that the exams were excessively short and rushed, that many CEs are biased against

chronic pain, and that single visits are not adequate assessments of complex claimants. As we will see in ALJ data, representatives can often be successful at this argumentation, since all but one ALJ also questioned the quality of CE exams along the same lines.

To summarize, I use the testimony of Judge Adar of the importance of legal representatives:

The [issue] is that people usually don't get lawyers until they're in front of the ALJ, [but] having the claimant representative involved I believe is so helpful. I found those cases so much easier...because they could find the medical evidence, they could do, quite frankly, a lot of the work that we would need to do, instead of the agency interviewing the person, sending them out for CEs, requesting medical records...going through the records and presenting things that are going to be helpful. I thought they were tremendously valuable.

### *Decision-making by ALJs*

When asked why there exists such a large variation between DDS and ALJ decisions on chronic pain claims, ALJs cite four factors:

1. Legal representatives providing records, evidence, and analysis
2. ALJ/court attorney training and experience
3. Being in-person with claimants
4. Claimants getting sicker over long wait times

When asked about large variation between ALJ decisions, ALJs cite three factors:

1. Personal biases
2. Inconsistent training
3. The nature of subjective 'gestalt' decision-making

All ALJs note the difficulty and complexity of making decisions on chronic pain claims, commenting on the inherent "subjectivity" built into decisions. ALJs make decisions in a gestalt way, as Judge Christopher comments: "the problem with pain is it really comes down to a judgement call ...it's a subjective analysis of everything you have in front of you". Though they share apprehension about such subjectivity as the SSA does, ALJs note that this subjective gestalt consideration is the true and only way to do what the SSA says to do, which is to make a decision about the disabling nature of symptoms using *all* of the evidence available to them. The Disability Examiner also shared this view for pain decision-making. ALJs feel that this type of decision-making is "what judges do", and that their training and experience as court attorneys and judges make them most equipped within the DDP to make decisions of this nature. Though DDS adjudicators and ALJs alike most consider consistency in medical records as the Rulings stipulate, ALJs say that these cases need an in-person component to aide in considerations of consistency. This is due both to the complexity and number of factors to be considered and by access issues faced by poorer claimants, who have fewer records, needed evidence, treatment (even when more testing or provider notes are requested by ALJs), and lack of consistent providers across medical visits. Judges take access issues into account. Judge Adar summarizes:

The DDS doesn't have all the medical evidence, but even when it does, it often doesn't make the right decision. But I don't know how they could make a good decision on pain. I think it has to seen by an ALJ...there has to be someone who sees and talks to and interviews this person to be able to make some determinations and focus the inquiry appropriately...I don't know how DDS

would be able to do that in the way that they're set up now...a skilled judge, which not all judges are, can focus and elicit testimony that's very helpful.

Judge Adar's comment shows how ALJs use the hearing to fill in gaps in the record by asking the claimant factual questions; however, she also indicates that ALJs have different skills and predispositions toward doing so. Judge Adar goes on:

When I was learning, I observed all the different judges in my office...there was one judge who...looked down, he never made contact, he spoke so quickly...every hearing I saw him do, the [claimant] was distressed at some point. I saw other people who made eye contact and really made an effort to listen to the person, and made sure that they felt like they were heard. Sometimes in disability you have to ask very personal and sensitive questions... those judges were going to have a different amount of information to work with.

Judges had varying quality of training, but all feel that trainings have decreased in quality over time, and that continuing education—which they find helpful—have decreased in frequency.

Judge Dodson comments that when she began in the 1980s:

We had six weeks of ALJ training. And during that six weeks, we had a combination of training on the law and regulations and medicine. And we had professors from the medical school in the Washington, D.C. area, as well as some of SSA's on-staff physicians, give us training...One of the appeals council members who had a background in pharmacology gave us training in medications.

Though ALJs acknowledge that cost-cutting likely contributes to reductions in continuing education and in-person trainings, they assert that it is not a factor that can be cut, as it results in lower decision-making quality and more variation across judges.

Besides eliciting information, the other major function of hearings is to assess claimant credibility. Due to the nature of complex cases with more subjective factors to consider, Disability Examiners and ALJs rely more heavily on their subjective perceptions of credibility than in other disability adjudications, even though the most recent SSA Ruling “removed the word “credibility” from the policy as to negate the exercise to judge claimants’ character or truthfulness” (SSR 16-3p). As Judge Peralta states: “We’re ordered by [the SSA] that we cannot use the word credibility. And we are not to determine the credibility of the witness. A judge’s job is to determine credibility. It’s just the nature of the job. But we cannot use the word credibility so we have to go through the whole sham of things that we can say that the claimants lack credibility”.

Assessing credibility appears, for DEs, in a phone call with the claimant, and for ALJs, in the courtroom. However, before even speaking with a claimant, biases for needing certain evidence (MRIs, X-rays, CAT scans, particular notations in provider notes, manual assessment) to prove pain, and prejudice against claimants alleging pain in general, enter into decision-making. Both adjudicators have a greater perception of subjectivity of pain and its’ measurements, and of malingering of pain claimants. Adjudicators’ “feeling” about whether or not a claimant is credible can even override imaging studies, as such objective evidence is considered by the SSA to verify the *possible* existence of pain, but not the severity needed to be considered disabled. Judge Peralta comments: “the MRI can say you’ve got herniated disc. I’ve got three herniated discs...[and] I worked through all my careers with it.” Adjudicators also have biases against specific diagnoses that they perceive as subjectively diagnosed—particularly fibromyalgia and

chronic fatigue syndrome. Legal representatives see this diagnosis bias too, as Mark's quote in the last section demonstrates, and one clerk confirms seeing it at the federal magistrate level as well. Even despite the SSA recognizing the tender point test as being valid for diagnosing fibromyalgia, some ALJs discount such tests as subjective and the validity of these diagnoses as being "diagnoses of exclusion", "fashions", and "mainly psychological". Judge Peralta states:

They're all on pain pills. They all have pain and they're 99% are women in their premenopausal stage who all of a sudden have a friend, and they've been involved in social media in getting referrals to other women who supposedly have this pain. And they just said "I have pain all over my body....[and] somatoform disorder—we used to call those hypochondriacs.

Though ALJs most consider consistency in medical records with in-person testimony as the Rulings stipulate, assessing credibility in the hearing often entails the use of a biased notion of what a disabled pain claimant should look like, the behaviors they should exhibit, and what activities a disabled person shouldn't be able to do. Despite SSA stipulation not to use "sit and squirm"—the expectation of what behavior a disabled person should exhibit—to assess credibility, most judges expect many behaviors of discomfort to manifest in the courtroom in order to render claimants' pain credible. Pertaining to activity bias, Judge Dodson comments:

The case law says that just being able to do every day chores on a sporadic basis does not mean that you can perform it in a sustained 40-hour week basis. Too many judges say, "Oh, he cooks a meal in the microwave and can do light grocery shopping and take the children to school. He's not disabled." And they don't look at the fact that the individual may then go back to the house after taking the kids to school and rest for three hours. They don't look at what that small chore does to the individual.

Her assessment, also confirmed by a clerk who reads ALJ decisions, is also confirmed by Judge Nelson, who considers: "are [claimants] still able to take care of their own house? Can they take care of their personal hygiene? Can they drive a car? Can they make meals? Can they shop in stores? And if you can do those simple things, you can go back to work".

The last mentioned factors that ALJs take into account is the testimony provided by Vocational Experts (VEs) and Medical Experts (though not all call on MEs), and CE exams. ALJs put a lot of weight into VE testimony, but some feel the lack of updating of the Dictionary of Occupational Titles (DOT) and its lack of consideration for geographic availability of jobs rendered testimony based on the DOT questionable. ALJs feel the quality of VEs is consistent, but complain about bias and inconsistent quality of CE exams and MEs. Like legal representatives, ALJs feel that a combination of CEs' lack of medical records provided by DDS, financial incentive to conduct quick and superficial exams, and bias against pain claims render the quality of many of their exams questionable.

An important note is that, from a systemic perspective, ALJs feel that recent pressure by the SSA for ALJs move more quickly through their caseload has changed and compromised their decision-making. Judge Jacey explains:

There's been a lot of pressure by the government to do cases faster and faster. So some of [my procedures] were more true [before] than today because judges just don't have the time to sit through conflicting evidence as much as they used to have... I know some that say, "I don't have time to look at the claimant. I look at the medical evidence and that's it"...it definitely affects the quality in the more difficult cases... if you're worried about your track record on cases, then

holding cases in order to get medical records can be a problem...It's important to spend time with a case, and if you don't have that time, you're not giving due justice.

ALJs are concerned that this pressure compromises their prior independence from Social Security, central to valid decision-making. Judge Dodson expresses feeling “under the thumb of the administration” even though ALJs are “theoretically protected by the Administrative Procedure Act”. They view the restoration of their independence and ability to give due time to cases as central to improving the DDP. In general, ALJs feel an inability to register feedback to the SSA, which compromises the DDP.

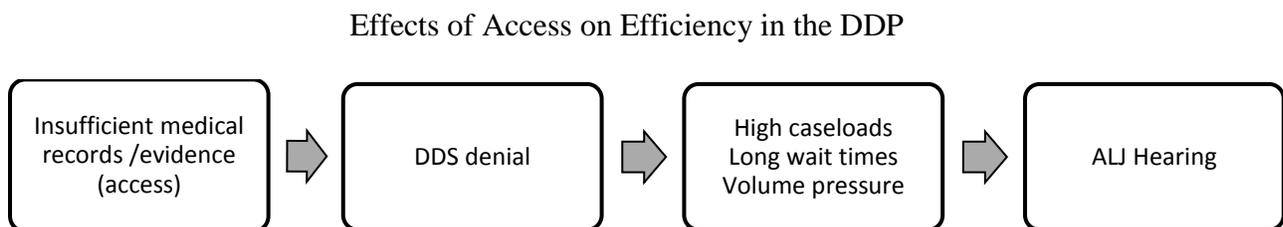
### Discussion: Issues to be Resolved

Phases I and II of this study provide data and analysis on inconsistency in the evaluation of chronic pain from several levels of analysis in the DDP. In phase I, interviews with claimants, treating physicians, and CEs yielded information from the medical and state levels, and verified the centrality of understanding inconsistency between state and legal institutional decision-making. Phase II provides data on the legal institutional processes of the DDP, as well as ALJ attributions about state-legal decision differences in decision-making, as well as differences across ALJs. It is noteworthy that ALJ attributions were highly consistent with findings from the 1987 IOM Report on Pain (pp 74-6).

In this section, I integrate findings from both studies—across 44 interviews with claimants, CEs, a DE, legal representatives, clerks, and ALJs in the DDP—to identify six issues to be resolved for efficient and reliable evaluation of chronic pain across the DDP<sup>4</sup>. In the next section, I provide recommendations to resolve these issues.

Six issues to be resolved for efficient and reliable evaluation of chronic pain:

1. Lack of access to information, medical records, and adequate evidence
2. Volume pressure and incentivization to process cases quickly
3. Bias and discrimination based on pain, evidence and diagnosis
4. Insufficient specificity for complex decision-making
5. Inconsistent and insufficient training
6. Lack of feedback mechanisms in the SSA



**Figure 1**

<sup>4</sup> See Berkowitz (2016), the Phase I study, for background data to conclusions in this section

**Issue #1 – Lack of access to medical records, evidence, and information**

The most pressing problem for efficient and valid decision-making for chronic pain claims is issues of access: access to medical records, evidence, and information. Though the DDS is responsible for gathering medical records, requesting outstanding evidence, and providing information to all constituents of the DDP, interviewee populations across this study—and the 1987 IOM Report—validate that a significant number of medical records are left incomplete when processed. While this is a problem for all disability claims, it particularly harms claimants with chronic pain, whose cases mostly depend on a complex adjudication of multiple factors from the medical record.

Three reasons emerge to explain the significant lack of medical records and evidence: 1) healthcare providers' non-compliance with DDS requests; 2) healthcare providers' inability to send medical records within the allotted time given by DDS before processing requests; 3) claimants' lack of access to healthcare, which especially affects poorer claimants. Actors across the DDP experience resistance from healthcare providers and organizations to providing records and evidence, no matter which constituent requests them; however, representatives are more successful with getting records and evidence. Some providers charge large sums of money (\$160-300) to fill out information, and certain medical organizations even have policies prohibiting their providers from helping patients with the DDP, namely Kaiser and community health centers, due either to perceived cost, the perception that the role of healthcare is to “treat” patients rather than fill out paperwork, and negative and misinformed perceptions of disability.

This study validates prior research finding that claimants with complex cases face a “run around” between doctors due to specialization and skepticism of pain by physicians (Trawalter et al. 2012; Wailoo 2014; Berkowitz 2015; 2016; Pryma 2017), and that the mistreatment faced through this process—especially highlighted in the data are worker's comp and Kaiser—contributes to worsening of patients' conditions until pain may become disabling when it was not before (IOM Report 1987; Tellier et al. 2013; Loeser and Schatman 2017). Additionally, even helpful providers are often ignorant of what evidence is needed and how to fill out DDP forms (IOM Report 1987; Fitzpatrick *DisabilitySecrets*; Laurence *ibid*). Resistance of treating physicians to labeling their patients as “disabled” and systematic non-involvement of medical organizations in helping patients apply for disability manifests in insufficient medical evidence for processing applications.

Additionally, all interviewee populations affirm that claimants have a difficult time accessing and understanding information about the DDP. Throughout the application process, the case of multimorbidity manifests in confusion on what claimants should include in their application, and discrepancies between what evaluators need and what applicants—and their treating physicians—provide (*ibid*; Stanley 2016). Claimants have many conditions—some of which do not appear as Listings—and they are unsure of which to list as primary and how to indicate their relations to one another. No interviewed claimants were able to find information on establishing medical equivalences to Listings, which legal literature and representatives say is helpful for establishing disability for many of their cases (*ibid*).

These factors contribute to a large number of cases that are insufficient for processing and add to the backlog of disability cases that will necessarily be denied at the DDS level and continue to an

ALJ hearing (see Figure 1). Claimants' cases take an average of three years to get to ALJ hearings (though the national average is around 1.5 years), where claimants are statistically highly likely to be granted disability (a central factor being that representatives gather medical records). This waiting time contributes to the worsening of claimants' health, financial and familial status (IOM Report 1987; Soss and Keiser 2006; Keiser 2010). Though representatives are central to resolving all these issues, they are financially disincentivized from getting involved until later stages, as they are paid more the longer cases are pending.

### **Issue #2 – Volume pressure and incentivization to process cases quickly**

It is widely acknowledged that there is a backlog in disability cases, resulting in high caseloads for adjudicators. The SSA has stated clearly that the 10% decrease in the core operating budget between 2010-2016 has affected the agency's ability to deliver services due to a shrinking staff while application numbers rise (Romig 2017). This decrease in funding has resulted in higher case backlogs and longer waits for decisions (ibid). Additionally, many constituents are concerned that the SSA has prioritized speed over accuracy, and different constituents allege that volume pressure systematically causes the denial or allowance of more cases (Van de Water 2015). In opposition to those alleging that more cases are being allowed, Van de Water (2015) notes that allowance rates have gone down at the same time as volume pressure has gone up, though many factors affect these rates. However, research by Keiser (2010) demonstrates that when DDS bureaucrats have to make decisions more quickly, they are more likely to deny cases. In the current study, ALJs feel that the SSA has put pressure on them to process claims so quickly that it "affects the quality in the more difficult cases" and does not allow for "due justice" to be given to claimants. Regardless of system-wide decision-making skews toward denials or allowances, Issue #1 demonstrates the severity of consequences for chronic pain claimants—and all claimants with complex cases—if ALJs feel that they do not have time to request needed evidence and read through complex files. ALJs express great concern that this pressure compromises ALJs' prior independence from Social Security through the Administrative Procedure Act. Claimants, legal representatives, and ALJs also feel that volume incentivization affects the quality of CE exams.

### **Issue #3: Bias and discrimination based on evidence and pain diagnosis**

This research confirms prior research and court cases showing that bias and discrimination about chronic pain enters at all levels of the DDP (Finch 2005; Purvis 2011; Pryma 2017). As discussed in Issue #1, healthcare providers are often skeptical and dismissive of chronic pain, leading to worsening of patients' conditions and insufficient medical evidence for processing claims. This same bias exists in DDP decision-making, where adjudicators' "feeling" about whether or not a claimant is credible can even override consistent imaging studies that substantiate pain claims, regardless of SSA Rulings. Interviewed CEs and one ALJ were completely reliant upon imaging studies to verify credibility, though this is not consonant with SSA Rulings about all factors needing to be considered together, and it is particularly problematic given the issue of access. All but one interviewed claimant had *multiple* objective indicators of severe chronic pain—including imaging studies and orthopedic surgeries—but were still denied at the DDS level. Some legal representatives note that this is the reason they do not take on chronic pain cases (or other cases with complexity and subjective factors) earlier: that no amount of evidence provided leads to a disability allowance for these claimants. ALJs rely on "sit and squirm" behavior in court and expectations of what a disabled pain claimant should look

like to assess credibility, regardless of whether new SSA Rulings state that assessing credibility is not within the purview of adjudicators. Particular prejudices against what are perceived as “diagnoses of exclusion”, like fibromyalgia, can result in discrimination against these claimants, regardless of Rulings by the SSA verifying them and their evidentiary bases like the tender point test. Importantly, as two-thirds of fibromyalgia patients are women, there is a strong gender component to such discrimination, as previous studies have also shown (Purvis 2011; Pryma 2017). In sum, when faced with complexity of decision-making in these cases and perhaps because of the strength of such cultural biases, adjudicators discriminate against claimants in these cases.

#### **Issue #4: Insufficient specificity for complex decision-making for DDP evaluators and examiners**

All decision-makers comment that chronic pain cases—and other cases with complex factors to take into account—are difficult and are more subjective. The SSA Ruling *16-3p* on evaluating symptoms, including pain, gives a clear and comprehensive list of factors to take into account when evaluating chronic pain, but decision-makers are not clear on how to take these into account together, which is one central factor contributing to overreliance on imaging studies. Though ALJs feel most able to adjudicate such cases because of their attorney experience and training, they comment that good legal representatives’ distillation of the case is a central help to such complex decision-making—a help not all claimants have access to. Ultimately, if decision-makers are ill-equipped for complex decision-making, they are more likely to rely on biases in their adjudications.

#### **Issue #5: Inconsistent and insufficient training for DDP evaluators and examiners**

ALJs note inconsistency across regions in their training, all feel that trainings have decreased in quality over time, and that continuing education—which they found helpful—have decreased in frequency. Some complained that current computer-based trainings are too formulaic. ALJs assert that this results in poorer decision-making quality and more variation across judges. CEs say that SSA guidebooks provide them with general indications of what the CE report should look like, what terminology to use, and what the SSA wants to know about claimants from an evaluation, but CEs say guidebooks are not sufficient for evaluating these complex claimants. It is only the DE who feels that DE training is extensive and consistent across the SSA. Decision-makers with insufficient training are more likely to rely on biases in their adjudications.

#### **Issue #6: Lack of feedback mechanisms in the SSA**

Many decision-makers interviewed in this study have specific feedback to improve the DDP, but experience a lack of mechanisms within the SSA to provide it. Some had participated in studies before, commenting to me that they had little hope that their feedback to me would do anything because they had not seen change from their feedback prior. These constituents feel that the SSA is deliberately opaque and resistant to feedback, which compromises the relationship between adjudicators and the SSA.

### **Policy Recommendations**

Importantly, findings from phase II of this study further substantiate recommendations made in phase I. Below numbered recommendations, I suggest possible concrete implementations.

1. **Establish ‘complex symptomatology’ as a category of claimant (internally within SSA).** Claimants with complex symptomatology/multimorbidity have complex and specific resource needs to be addressed.
  - a. ***An interactive online questionnaire*** to assess if applicants may fit into this category prior to the application. Variables to consider could be: number of conditions listed, number of providers, existence of symptom-based conditions, etc. Based on claimants’ responses, tailored information could be provided (see below).
  - b. ***Application tracking:*** as these cases are more complex, they may need to be “tracked” to DDS adjudicators more specially trained to evaluate complex cases.
2. **Provide targeted resources for this claimant population.** “User-based design” or “human-centered design”—beginning with focus groups with claimants/advocates and statistical analysis of their application usage—could be used to further identify and categorize resource and implementation needs for this population. Other areas of the government are implementing these resources, including the SSA, and this resource could be extended to this population (<https://www.usability.gov/what-and-why/user-centered-design.html>; SSA Digital Government Strategy 2012). Without such resources, claimants improperly fill out claims, and/or claims have insufficient evidence to be processed, contributing to a backlog of cases necessarily denied at the DDS level.
  - a. ***Representatives:*** legal representatives are currently the resolution to access issues faced by this claimant population; therefore, this study suggests that representatives to help these claimants, either within DDS or outsourced, is the ideal solution (see pages 6-8 for specifics). If outsourced, financial disincentivization for outside representatives to get involved early in the process needs to change; otherwise, subsidies could also be given to current advocacy organizations to be expanded, as is currently being done in California (see page 8). Due to differences across regions in accessibility of healthcare, such representation cannot vary by state.
  - b. ***More accessible and tailored information for claimants and providers:*** the SSA publishes much information on the DDP for both populations (including evidentiary forms like the RFC), but they are not accessed easily by these populations. Though this study shows that just providing better resources to claimants and providers will not resolve access issues for many claimants, nonetheless, population-tailored online and contact-based (e.g. emailed) information for claimants will still be helpful. For instance, information on available resources in claimants’ geographic region is one element to be included.
  - c. ***Standardized evidentiary requests/needs from providers:*** for this population of claimants, evidence provided by healthcare providers and requested by DDS agents is highly inconsistent, leading to inconsistency in evaluation; therefore, developing specific and standardized evidentiary requests/needs is advised.
  - d. ***More financial incentive for providers to provide evidence:*** current SSA payments to providers for providing needed evidence are considered by many providers to be insufficient, so increasing payment could incentivize providers.

- e. **Evidentiary requirements for providers:** due to healthcare non-compliance, an ideal solution would be a legal requirement for healthcare providers to provide specific/standardized evidence to equalize access.
  - f. **Financial aid:** Due to current inefficiency in decision-making for these claimants, many claimants have average three-year waiting periods before they reach the ALJ hearing, over which time they suffer deteriorating health and poverty. Sustaining financial resources should be made available for those with long waits. Claimants suggested allowances for limited employment/activity (e.g. schooling, *Ticket-to-Work* expansion) that does not affect application outcomes, organizing/subsidizing employers to hire part-time disability applicants, and providing short-term subsidies/loans.
3. **Develop specific guidelines and decision support for complex decision-making for DDP evaluators and examiners.** Ruling *16-3p* is a more detailed, balanced, and inclusive Ruling for pain evaluation. It also adds complexity and many subjective factors into determination without clarity for *how* to evaluate these factors in conjunction with one another, resulting in inconsistency and utilization of bias. Therefore, developing specific guidelines for complex decision-making is advised.
    - a. **Decision support tools**, like checklists, have become highly utilized in healthcare provision to aide in complex decision-making. Reductions in provider mistakes and use of bias has been documented when providers use checklists (Gawande 2010; Nordell 2017). Checklists could include each factor in SSR *16-3p* that must be considered to prompt adjudicators and help with complexity of consideration using those factors. User-based/human-centered design could help create decision-support tools that adjudicators find helpful (see Recommendation 2).
  4. **Provide consistent high-quality trainings and continuing education on complex symptomatology for DDP evaluators and examiners.** User-based/human-centered design for courses can be utilized. ALJs and CEs cite the need for more frequent continuing education, and ALJs cite the importance of such training be in-person to promote conferring with other ALJs on decision-making strategies. Some factors to be included: bias training with special focus on common documented biases (e.g. fibromyalgia) and awareness that volume increases using biases. Findings from Keiser (2010) also suggests that “information sharing” about allowance rates across different decision-making levels—e.g. making DDS bureaucrats aware of ALJ allowance rates—increases consistency across institutions. Additionally, the National Conference of ALJs has extensive trainings available that could be integrated, or ALJs could be incentivized/subsidized to attend.
  5. **Assess decision-making bias.** Statistical analyses of decision-makers’ determinations according to common biases (e.g. allowance rates across ALJs on fibromyalgia determinations) and/or audit studies (sending standardized claimants through the DDP) could assess decision-making bias in the DDP.
  6. **Provide feedback mechanisms in the SSA.** A clear way for decision-makers and representatives to provide feedback to improve the DDP would be useful. User-based/human-centered design is also a useful way to integrate constituents into the DDP (see Recommendation 2).
  7. **Hire more adjudicators and support staff.** It is hoped that the above recommendations will help alleviate high caseloads and volume pressure on adjudicators in lieu of the fact

that hiring more staff incurs costs to the SSA—an option not always available due to agency funding levels and in the context of a shrinking operating budget. Adverse effects of budgetary-induced staff cuts on record-high workloads with fewer resources have been noted (Romig 2016; SSA FY 2017 Fiscal Budget Overview), and it is hoped that this study further clarifies the costs of high caseloads and volume pressure in support of SSA requests for the necessary funds to cover staffing (SSA FY 2017 Fiscal Budget Overview).

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