

Balance of Powers: Social Security and the Mentally Disabled, 1980–1985

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FOR NEARLY HALF A CENTURY SOCIAL SECURITY WAS a cherished benefit system familiar to most Americans. In contrast, the agency that administers the many programs of that benefit system, the Social Security Administration, was unfamiliar or viewed as a faceless bureaucracy sending out checks, its contact with the public limited to district offices in gray public buildings. Social Security, admittedly imperfect and subject to constant tinkering, was still largely respected for its fairness and professionalism and admired for its compassionate concern for those among us too old or disabled to continue working. But, as we entered the 1980s, attitudes began to change, especially about Social Security's disability programs, Social Security Disability Insurance (SSDI), and Supplemental Security Income (SSI). (SSDI is a social insurance program designed to replace income for workers forced to retire early due to disability. SSI is a welfare program, designed to provide income for the elderly and the poor who are disabled. Both programs are administered by the Social Security Administration and share a common definition of disability and a common disability determination system.)

In a recent monograph, Berkowitz (1987) presents a comprehensive review of disability policy in the United States, covering some of the same material we discuss in this essay. His historical view is longer and broader, focusing attention on the complex tensions between

income maintenance and vocational rehabilitation, between labor force withdrawal and labor force participation. He concludes: "America remains without a disability policy" (Berkowitz 1987, 239). It needs fundamental reform to coordinate disparate programs and to promote the independence of the physically and mentally impaired through effective rehabilitation. Viewed from his larger perspective, we would agree with his analysis and conclusions. Our view is narrower and more focused, however.

This article is about the changes in public attitudes toward Social Security, focusing on the disability programs and the mentally ill. We report on incremental steps to correct a painful episode for mentally disabled Social Security beneficiaries. We analyze an effort to restore their income support so that they might go on to be rehabilitated. We will examine the balance of powers among the executive, judicial, and legislative branches of government in the making of social policy for the mentally disabled, circa 1980, and consider the role played by research in achieving balance. Research helped to define problems with disability policy (cf. U.S. General Accounting Office 1981) and also assisted in defining solutions (cf. Anthony and Jansen 1984; Meyerson 1983; American Psychiatric Association 1987). The story is not a comprehensive or totally objective account of the relevant circumstances, decisions, and events. We listened to competing versions and tried to be open-minded about what occurred and why, but acknowledge our concern for the fate of the seriously and chronically mentally ill individuals who depend on Social Security's disability benefits programs to maintain themselves outside of institutions. Thousands of these vulnerable individuals were among the many more thousands of other disabled persons whose Social Security entitlements were terminated, leaving them bereft of the cash allowances that most depended on to live.

The focus of this account is on how it came to pass that, despite a national policy of community care of three decades' standing, thousands of mentally disabled beneficiaries were cut from the disability rolls. How did it happen that Social Security policies toward the disabled—traditionally the outcome of counterbalancing executive, legislative, and judicial input—inadvertently produced a travesty of mental health policy during the period of 1980 to 1985 (Goldman and Gattozzi 1988)?

This article strives to be useful by shedding light on missteps in

disability policy making and administrative procedures and by documenting why and how the balance of executive, legislative, and judicial powers was upset. Not simply a cautionary tale, it may also hearten readers by recounting how the balance of powers was restored and Social Security returned to righteous paths. Government fouled up and the governed suffered, but government can and did correct itself.

Cutting the Disability Rolls

The months following the presidential election of 1980 were exceptionally busy for the winners. Their leader had gotten the voters' mandate for his conservative fiscal agenda to slow, perhaps halt or even reverse, the growth of federal domestic spending. Fired by this vision, transition team members, assisted by career civil servants, delved into programs throughout the executive branch, looking for ways to cut costs. The new president's first budget documents gave ample evidence of the success of their diligent pursuit of dollar-saving devices.

One measure, however, was destined to boomerang on its authors and deal the administration a stunning public relations blow. Rarely noticed in the intoxicating rush of changeover to an administration with different priorities from its predecessor, this measure called for the Social Security Administration to review its disability insurance rolls "to insure that only the truly disabled receive disability benefits." The payoff, literally and politically, was to be impressive: Savings of \$50 million in the current fiscal year (ending September 30, 1981) were scheduled, projected to attain a total of \$3.45 billion in savings in the following five years (U.S. Office of Management and Budget 1981).

The savings were to flow from an administrative initiative: that is, an executive action needing no new legislative authority. The executive had simply to order its agency—which it did, in March—to begin immediately an intensive program of reviewing the eligibility of beneficiaries enrolled in the Social Security Disability Insurance (SSDI) program. Nonetheless, there was a legislative warrant for the action, a happenstance that was to cloud the issue of responsibility for the untoward consequences of the reviews in the months to come.

The previous Congress had passed the Disability Amendments of

1980, among whose provisions was a mandate that Social Security review the eligibility of all disability insurance beneficiaries, except those listed as permanently disabled, every three years. The Senate report on the bill declared that disabled recipients of Social Security's Supplemental Security Income (SSI) benefits were also to be included in the review program. To allow sufficient time for preparation, the law stated that this "periodic review" was to begin in January 1982, and take three years to attain full implementation. An estimated savings of \$218 million in savings was projected for the period of 1982 to 1985 (Dilley 1987).

The provision was seen as a good government measure; no more than a reminder to Social Security to carry out its review function, it had attracted little discussion pro or con. The main thrust of the law was on work incentives, meant to encourage disabled individuals to leave the benefit rolls, and on increased federal control over the disability determination procedures used by state agencies under contract to Social Security and the appeal decisions made by Social Security's corps of administrative law judges (Koitz 1982).

Indeed, even before and ever since the incorporation of disability benefits as Title II of the Social Security Act in 1956, Congress found reason to try to offset the judiciary's "liberalizing" influence on disability determinations (Stone 1984; Berkowitz 1987). Given the widespread perception in the late 1970s that the costs of Social Security's income maintenance programs for disabled persons might be getting out of hand, congressional vigilance over the putative judicial exacerbation of the situation reached new heights. The Senate version of the Disability Amendments of 1980 had a provision that would have radically circumscribed federal court review of disability decisions. The provision was deleted from the final draft of the bill by the House-Senate conference committee, however, because of members' uncertainty about its implications.

So matters stood when the Reagan administration took office in January 1981: Social Security's DI and SSI programs of income maintenance of disabled Americans, among whom were some 550,000 mentally disabled citizens (Anderson 1982), appeared to be running as usual in the politically acceptable channels sanctioned by the executive, legislative, and judicial branches acting in dynamic balance.

But the appearance was deceptive. Ironically, it was the Reagan administration's budget-driven initiative of March 1981 that exposed

the reality. Ironic because the initiative, itself a potentially over-balancing flex of executive muscle, revealed the excesses to which the executive's own agency had already gone in gravely flawed, albeit well-intentioned, attempts to control the costs of the disability benefits programs.

What the Lawyers Saw

As noted, in March 1981 the administration ordered the Social Security Administration (SSA) to begin an accelerated schedule of continuing disability investigations (CDIs). By the end of that year, advocates representing disabled people were learning of thousands of persons being denied benefits upon initial application or cut from the rolls following a CDI procedure, with mentally disabled people disproportionately represented among them. Mentally disabled beneficiaries accounted for about 11 percent of the SSDI roll but represented nearly 30 percent of those whose benefits were cut (Pepper 1982).

At first, lawyers representing mentally disabled people could see no pattern in the decisions affecting their clients, noting only that the termination notices were usually accompanied by the finding that the person could perform low-stress, unskilled work. They had no inkling of the methods SSA was using and whether those methods were lawful (L.S. Rubenstein, personal communication, 1987).

According to the Social Security Act (Para. 223d), "disability" requires that a worker's mental or physical impairment be "of such severity that he is not only unable to do his previous work but cannot, considering his age, education and previous work experience, engage in any kind of substantial gainful work which exists in the national economy, regardless of whether such work exists in the immediate area in which he lives, or whether a specific job vacancy exists for him, or whether he would be hired if he applied for work." Age, education, and previous work experience are referred to as "vocational factors" and are used only to determine whether a person is able to perform work.

SSA regulations and guidelines define a five-level sequential evaluation process for making disability determination decisions. The process begins when a worker files for benefits at a local SSA office, whereupon a claims examiner collects medical and other information. Claims can

be denied here, at the first level, for nonmedical reasons, e.g., the person is earning more than \$300 per month. If there is no denial for nonmedical reasons, all claim information is sent to the state disability determination service (DDS), where an examiner may order additional medical and other information. Then the examiner and a DDS physician together consider the evidence in the following terms.

- Does the person have a “severe” impairment, one that “significantly limits” physical or mental capacity to do basic work? If no such impairment is found, the claim is denied.
- If the person does have a severe impairment expected to result in death or last at least 12 months absence from work, does that impairment meet or equal the degree of severity specified in SSA’s “medical listings of impairments”? If so, the claim is allowed.
- If not, can the person still perform his past work? This determination is based on an assessment of the person’s “residual functional capacity,” i.e., his/her actual physical and mental capacities. If it is found that past work can be done, the claim is denied.
- If the person is found unable to do past work, can the person do any work existing anywhere in the national economy? This determination is based on results of the assessment of residual functional capacity plus consideration of vocational factors. If a job calling for such abilities is listed in a government book of occupational titles, regardless of its location or availability, the claim is denied.

An individual denied benefits at any level of the determination process is advised of his/her right to appeal. Thus, a person whose claim is denied by the DDS has the right to have the claim reconsidered by other DDS personnel if requested within 60 days. If again denied, the person may request, within 60 days, a hearing before an administrative law judge (an experienced trial attorney trained to adjudicate disability claims). If denied at this level, the person has 60 days within which to request a review by the Appeals Council, the last Social Security administrative forum for appeal. If the claim is still not allowed, the person has the right to appeal to the federal district court within 60 days.

The first lawsuit to attempt a systemic challenge to the denials and benefit terminations of mentally disabled persons, *H.J. v. Schweiker*, was filed in Utah. Attorneys’ inability to fashion a particularized legal

claim led the court to deny plaintiff's motion for a preliminary injunction in June 1982. A few months earlier, however, attorneys in Minnesota had come into possession of internal SSA documents that suggested there was a pattern in the decisions, one that violated the program's requirements for a realistic assessment of the person's actual capacity to work. The documents offered sufficient basis for a lawsuit, *Mental Health Association of Minnesota v. Schweiker*,¹ a class action on behalf of all severely mentally ill individuals in SSA's Chicago region (covering six states) who had been denied or terminated from benefits in consequence of the policy implicit in the putative pattern. Filed in May 1982, it sought an injunction against the policy and readjudication of each of the plaintiff's claims (Rubenstein, Gattozzi, and Goldman 1988).

The lawsuit alleged that the policy violated the requirement of the Social Security Act, specified in SSA regulations spelling out the sequential evaluation process, that each person receive an individualized assessment of ability to work, or "residual functional capacity." Instead, the suit alleged, SSA substituted an unauthorized presumption that a mentally ill person whose condition did not meet the listings could perform unskilled work. The allegations were substantiated to the satisfaction of the judge, who ruled in favor of the plaintiffs and declared the SSA policy to be "arbitrary, capricious, irrational, and an abuse of discretion."

The Subregulatory Definition of Disability

The SSA policy in question amounted to a second definition of disability at variance with the one explicated in regulations. This second definition was found in the program operational manual system (POMS) and other guidance to state DDSs that are not required to be published and hence are not open to public scrutiny. In a study performed in late 1982, the U.S. Government Accounting Office discovered that SSA policy guidance to DDSs "resulted in a virtual presumption" that an individual who does not meet the listings retains the residual functional capacity to do unskilled work. The GAO tracked the evolution

¹ 554 Minn. Suppl. 157 (1982).

of this policy guidance to the SSA Informational Digest 79-32 of April 1979 (McGough 1983).

According to Dilley (1987), it seems very likely that SSA's sub-regulatory changes were motivated by congressional pressure during the 1970s to cut program costs. What changed was "the 'adjudicative climate' which operated in that gray area of policy development at the state agency level and in communications between state and federal officials below the level of public regulatory action." Although SSA and Congress expressed concern about the ability of the courts to override, in effect, the regulations on disability decision making, it was agency policy makers themselves, spurred by congressional pressure, who could and did produce significant changes by altering the "adjudicative climate" within which the regulations were followed. As it happened, the congressional spur to cut costs during the 1970s was occurring about the same time as the culmination of an internal research project.

SSA policy on mental disability determination became fully evident when the agency was obliged to produce internal documents and answer questions during the discovery phase of *Mental Health Association of Minnesota v. Schweiker*. What emerged was that, by the late 1970s, the headquarters medical office staff was nearing the goal of its decade-long effort to achieve the "quantification of psychiatric impairments" (Nussbaum, Schneidmuhl, and Shaffer 1969). The one-page "Psychiatric Review Form" was being developed for this purpose. It consisted of 17 items denoting signs of mental illness that would generally appear in a conventional mental status examination, grouped in three categories called "effective intelligence," "affective status," and "reality contact." The examiner or physician completing the form rated the severity of each sign on a five-point scale, then made a summary rating for each category and/or the person's overall mental condition. Only if a person's amalgamated rating reached five was the person considered to be disabled (Rubenstein 1985).

In keeping with the attempt to maximize objectivity, the SSA medical staff also formulated the theory that mental disability could be determined without any independent examination of the person's capacity to work or even of his/her functional capacities in any worklike setting—areas in which little quantification of findings was possible. Rather, disability could be determined almost exclusively on the basis of signs and symptoms of mental illness (Rubenstein 1985). (SSA uses

this approach to assess disability in most body systems; it is not well substantiated by research evidence, especially with respect to mental impairment.)

The result of relying on this approach was that SSA examiners and physicians came to consider as redundant the determination of residual functional capacity. From their point of view, a claimant whose condition was not so severe as to meet the criteria specified in the listings was, *ipso facto*, not disabled.

But this assessment method not only constituted a second, sub-regulatory definition of disability, it was also at odds with current professional understanding of the nature of mental illness. By focusing principally on signs and symptoms, SSA ignored what research has shown, and most psychiatrists believe, to be of key relevance to a disability determination: the person's functional skills, which do not necessarily correlate with severity of signs and symptoms (Anthony and Jansen 1984).

It should be noted that this SSA view of disability assessment was in place well before the congressional Disability Amendments of 1980 that mandated a periodic review of the rolls and the Reagan administration's 1981 initiative to accelerate disability reviews. Indeed, as some have observed in retrospect, SSA's use of its "objective" approach to mental disability determinations might have gone unnoticed indefinitely were it not for the torrent of denials and terminations in the wake of the accelerated review program begun in 1981 (P.M. Owens 1987; J. Manes, personal communication 1987).

Be that as it might, as the numbers of those cut from the rolls mounted, a significant portion severely disabled and manifestly unable to work, the judiciary was acting, on appeal, to reinstate a record high rate of denied claims. Administrative law judges, reviewing claims *de novo* on the basis of the regulations (not privy, in fact, to SSA's extraregulatory guidance to DDSs), found two-thirds of disallowed claims to be valid in the year following the start of the accelerated review program; for mentally disabled claimants who appealed, the figure was 90 percent. And federal courts, as in *Mental Health Association of Minnesota v. Schweiker* case, were ruling against SSA and in favor of plaintiffs denied or terminated from benefits.

Meanwhile, as legal advocates for mentally disabled persons made their cases to the courts, others directed their concerns to the agency itself and the Congress.

Advocates' Efforts to Affect the Balance

Mental health interest groups, learning of what they considered egregiously inappropriate benefit terminations being made all around the country, tried at first to understand why they were occurring. Meetings with SSA representatives at the Baltimore headquarters, however, turned out to be more confrontational than illuminating (C. Koyanagi, personal communication, 1987). Congressional hearings were a far more effective forum for bringing the issues into focus.

Testifying before a Senate hearing on September 8, 1982, on behalf of a coalition of 17 mental health interest groups, J. Talbott, an American Psychiatric Association (APA) spokesman, cited some apparent causes for their assertion that SSA reviews "are being conducted in a manner contrary to sound medical practice and sound professional clinical practice" and are working "a special hardship upon mentally ill SSDI recipients who, by virtue of their illness itself, are particularly vulnerable." Among the causes, a serious shortage of mental health professionals on DDS medical staffs and SSA's use of outdated criteria (i.e., the listings). The spokesman noted that, although the APA had recommended several changes to the mental impairment listing, based on the 1980 revision of the field's standard, the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-III) (J. Folsom, letter to the commissioner of the Social Security Administration, 1982), SSA made no substantive changes in that section in its 1982 reissuance of the mental impairment listing.

SSA representatives who testified at hearings took the offensive in defending their policies generally and labelling the issues of the *Minnesota* lawsuit aberrations and departures from national policy. Top policy manager Paul Simmons (1982) declared: "If there are errors and failures in this program, they are not this administration's—they are the errors and failures of the U.S. government over time." Privately, however, the policy managers were uncertain whether the manifestly inappropriate terminations coming to light were accidental, arising from bureaucratic bugs, or were true albeit unintended consequences of their policy (P.B. Simmons, personal communication, 1987). Like all big government agencies—and Social Security is thought to be biggest of all—the handful of political appointees at the top depend on apolitical adherence to their directives by tens of thousands of managers, supervisors, and line-workers. There is absolutely no evidence even hinting that this

was not the case with Social Security during the period in question, the first Reagan term. Indeed, at the very beginning of that term, the highest-ranking civil servants of the SSA showed eagerness to cooperate with the politically appointed commissioner and his aides by bringing to their attention the results of internal studies which suggested large potential savings associated with disability eligibility reviews (Goldman and Gattozzi 1988). So it was not concern about sabotage that troubled SSA's policy managers, it was the formidably vast size, reach, and complexity of the bureaucracy itself that was showing itself to be less responsive to their control than they had thought it would be.

To turn down the political heat they were feeling, SSA policy managers took steps in 1982 to "improve" and "reform" their disability review procedures. These included institution of face-to-face interviews at the local office level for CDI cases chosen for review and a 20 percent reduction in the number of CDI cases to be reviewed during fiscal year 1983, lowering the number from about 806,000 to about 640,000 (U.S. Department of Health and Human Services, news release, Sept. 8, 1982).

Congressional hearings led to a bill, P.L. 97-455, enacted in January 1983, that relieved some of the pressures on both disability claimants appealing termination of their benefits and on SSA. One provision, due to expire in June 1984, continued payments and Medicare coverage to individuals dropped from the disability insurance rolls before October 1983, while they appealed (benefits had to be repaid if the appeal was lost). Another allowed Margaret Heckler, the Secretary of Health and Human Services, to slow down the triennial review of the disability rolls. The new law was regarded by disability advocates and their congressional allies as only a stopgap measure but, as Senator John Heinz (1982, 53) described it, "a step in the right direction toward reform of a process in serious disarray."

It was Senator Heinz who asked the U.S. General Accounting Office to investigate SSA's regulations and procedures for determining mental disability (see below), although his was far from being the first or the last hearing to probe SSA actions generally between 1981 and 1984. In common with several other Congress members on both sides of the aisle, he was initially moved to question the administration's policy on disability through hearing from constituents about the tragedies occurring as a result of Social Security benefit terminations. Although

Democrat members, traditional supporters of social welfare programs, were quickest and sharpest in condemning this administration policy, Republican members, nominally administration allies, eventually also responded to criticism voiced by professional interest groups, constituent concerns, and ongoing media coverage of the plight of individuals and families.

An Inadvertent Travesty of Mental Health Policy

Congressional interest in disability reviews continued unabated in 1983, with mental disability getting special attention. Not only were there tragic consequences to the individuals wrongfully deprived of their entitlements but, as Senator William Cohen pointed out, damage was being done to the national deinstitutionalization policy. "We are reversing a deliberate, calculated policy . . . of trying to move people out of institutional care into the community. . . . If you take away their subsistence . . . what you do is force them back into institutions because they have no place else to go. . . . Costs are going to be dramatically higher, which totally reverses the policy that we have pursued in the past decade" (Cohen 1983).

GAO testimony at a congressional hearing in April produced striking evidence of the questionable quality of SSA's methods of assessing psychiatric disability. GAO's clinical psychologist reviewed 40 denial and termination cases and agreed with the SSA decision in not a single one; she concluded that in 27 cases the individuals were unable to work in a competitive setting, and in 13 cases additional medical or psychosocial information was needed to make an informed decision (McGough 1983).

The GAO study cited several problem areas and, in response to questioning, one of the researchers pinpointed a key issue: SSA examiner evaluation of daily activity, which, perforce, was often made in the absence of professional mental health assistance. If a mentally disabled claimant said he could "push a broom, or fry an egg, or sit at a piano and hit a few of the keys," the examiner was likely to decide that, according to SSA's current guidelines, the claimant was able to perform low-stress, unskilled work (U.S. Senate 1983).

Just how far SSA's guidelines strayed from contemporary medical understanding of the condition of the typical mentally disabled claimant

emerged in other testimony. Scores of psychiatric research and clinical studies over the past two decades have demonstrated that antipsychotic medications are often highly effective in controlling the blatant symptoms of severely mentally ill persons, thus enabling them to leave total institutional care and live in sheltered community settings. Nevertheless, these drugs have been shown to have little effect on patients' ability to adapt to the ordinary psychosocial stresses of vocational functioning (Meyerson 1983).

GAO's psychologist summarized it well:

The purpose of deinstitutionalization is to assist individuals to work at the highest level that they can. The mental health people who work with chronically mentally ill try and help the patients undertake activities in the community . . . to go to day treatment or have sheltered work or a hobby or to socialize. This does not mean that these people are capable of functioning in a competitive world without support. . . . This is where the two parts of the government are at cross purposes" (MacLennan 1983).

The Administration at Bay

Members of mental health interest groups and SSA representatives continued to meet formally and informally during the early months of 1983. Advocates believed, however, that the agency was not acting in good faith. "They constantly talk about beginning to study problems we've been telling them about for over a year," one said, "but a lot of it is too little, too late." (Congressional Quarterly 1983) A meeting of SSA and APA representatives in late March seemed to produce a favorable climate for cooperation (though some worried it might be cooptation), specifically, psychiatric representation on an SSA advisory group being planned and possible adaptation of APA peer review methods to disability determinations (American Psychiatric Association 1983). But the political momentum generated by congressional hearings overtook this development.

A bill was introduced in the Senate that called for a temporary moratorium on mental disability reviews until SSA revised its review standards and procedures. The proposal promptly elicited sharp criticism from the administration. Mental health advocates were taken aback by what they considered a distorted reading of the bill's provisions

and an intransigent negative position on the question of the need for substantive changes in SSA disability determination procedures. In response, they called their own temporary moratorium on further discussions with SSA (M. Sabshin, letter to Secretary Heckler, May 26, 1983; Mental Health Association 1983).

Things were at an impasse. To many observers it seemed that SSA policy managers were of two minds: Review standards and procedures indeed appeared to be flawed and in need of correction, but the logic of the budget was inescapable. Full concession to the critics of the disability review program would probably cause the budgeted savings to disappear. SSA policy managers were instituting reforms as rapidly as possible to ameliorate the procedural problems they discovered while at the same time standing firm on the basic thrust of their policy. This strategy might have worked but for the vast inertia characteristic of a huge and complex government bureaucracy. "It was like trying to move a glacier backwards," one said later. "You can't. You can make it melt a little faster up front, but you can't push it back" (P.B. Simmons, personal communication, 1987).

At the height of the controversy, SSA's disability determination procedures were under legal challenge in more than 100 class-action lawsuits. Attorneys assigned to SSA's disability litigation staff, four at the beginning of 1982, were soon doubled in number and then doubled again (G. Imperato, personal communication, 1987). Although the Justice Department was taking an increasingly active part in defending SSA, in 1983 its third-ranking official, the U.S. Attorney for the Southern District of New York, refused to defend some cases after concluding that the agency's position was indefensible (Pear 1983). Moreover, in 1983 SSA faced two lawsuits brought by the Association of Administrative Law Judges, which charged that SSA pressured its members to reject appeals to workers denied disability benefits.

SSA resisted its legal foes at every turn. A notable example: Following its controversial policy of nonacquiescence, the agency declined to appeal yet refused to apply Court of Appeals rulings to identical issues in other cases in the same judicial circuit. This policy produced "a dramatic increase" in the number of motions to hold the secretary in contempt, according to SSA's own confidential study. Indeed, the study concluded that the agency's efforts to trim the disability rolls

had led to “a huge volume of adverse court decisions” and produced “a major crisis in litigation” (Pear 1983).

The public image of SSA, and the administration, got a big black mark with news reports that Sgt. Roy Benavidez, Vietnam veteran and winner of the Medal of Honor, had been cut off from receiving disability benefits awarded because of multiple war wounds (he was subsequently reinstated). The system truly was in disarray as, one after another, state DDSs, under court orders or those of their governors, suspended disability reviews. As one of SSA’s policy managers later observed, the agency was at the center of the worst public policy debacle he had seen in 20 years of government service (P.B. Simmons, personal communication, 1987).

Advocates Win a Seat at the Administration’s Table

In mid-1983 the administration yielded to the political and health-professional opposition. The Secretary of Health and Human Services acknowledged that, despite a 60 percent increase in federal funding for state agencies and a one-third increase in their staffs, the reviews sometimes resulted in disabled persons’ being improperly cut from the rolls. The secretary noted that state agencies were dropping beneficiaries from the rolls at more than twice the expected rate—45 percent of the first 750,000 cases reviewed—because SSA had assigned review priority to cases whose characteristics (e.g., age, year of initial allowance) indicated they would be more likely than other cases to be able to return to work (M.M. Heckler, news release statement, June 7, 1983).

The secretary announced a number of reforms. Among them, random selection of cases to be sent for state review; permanent exemption from review of 200,000 more cases, bringing the total exempted to more than a million (37 percent of the rolls); and acceleration of a top-to-bottom review of disability program standards and procedures in consultation with appropriate experts. Further, specifically affecting mentally disabled beneficiaries was the temporary exemption of 135,000 mental impairment cases pending consultation with outside mental health professionals on revision of the listings used to determine mental disability. The administration also agreed that, once acceptable revisions had been adopted, SSA would undertake to identify and rereview

mentally impaired persons who had not appealed the termination of their benefits.

The advocates thus won a seat at the table where new policy for SSA mental disability determinations would be set. For this purpose a special SSA work group was formed under the joint sponsorship of SSA and APA; it included psychiatrists, psychologists, and other professionals from both government and the private sector concerned with the assessment of mental impairment. Their meetings, begun in July 1983, culminated in February 1985 with publication of the revised mental impairment listing (U.S. Department of Health and Human Services 1985a). (Two other work groups were formed, one of which developed a statement on work and mental impairment that was published later as an official policy guideline [U.S. Department of Health and Human Services 1985b].)

During the months of the special work group's deliberations, Congress and the courts continued their efforts to right the balance—to change the statutory basis and counter the illegal outcomes of the disability review process. That the executive had conceded the need for basic revision did not deter Congress, in the Disability Reform Act of October 1984, from mandating and setting a time limit on revision of the listings in consultation with outside experts. Nevertheless, the prior establishment of the SSA-APA mental impairment standards work group was indeed a genuine departure for SSA in the entry it afforded outsiders to the ground level of agency policy making. Their inclusion may be seen as a signal of the executive's willingness to rebalance the powers in the making of disability policy.

Did Research Make a Difference?

As this account indicates, the disability eligibility criteria for mental impairment became a major focus of the reform effort. Before the departure of 1983–1985, SSA relied almost exclusively on the expertise of its own medical staff, which, in turn, referred mainly to the agency's unique experience in disability determination (N. Dapper, personal communication, 1987; G. Imperato, personal communication, 1987). SSA staff conducted little research; what research it did was largely focused on internal reliability and “assessment form” development and little concerned with the validity of the agency's disability assessments

or the interface of its activities with mainstream psychiatric thinking. Once policies and procedures were established in this insular setting, SSA, in accordance with standard government procedures, solicited outside expert comment and accepted or rejected suggestions for change at its own discretion.

An extraordinary fallout of the debates over disability review issues was the extent to which psychiatric research played a part. One example of the role of research in the events of 1981–1984 started when attorneys for mentally disabled plaintiffs in the *Minnesota* case hesitated to introduce expert psychiatric and rehabilitation witnesses to help make their case. They were well aware that Congress and the courts allowed SSA great leeway in formulating the rules used to administer its program, including rules covering what constitutes a disability and what inferences may be drawn from evidence submitted by claimants. The attorneys were concerned lest their questioning the medical basis of SSA rules would be seen as merely a disagreement with SSA over medical issues—a matter over which the court would not second-guess SSA (L.S. Rubenstein, personal communication, 1987).

The attorneys decided to risk it and were successful. The research evidence presented to the court, although not gathered in the context of making disability determinations in a public program, was a key factor in the winning of the case. It clearly demonstrated the error in SSA's presumption of not being disabled if a claimant's impairment failed to meet the listings. More, SSA not only failed to present evidence of its own or others to counter plaintiffs' researchers, its testimony revealed that it was not in touch with contemporary thinking about means of assessing long-term disabling effects of severe mental illness (Rubenstein 1985). In this instance, up-to-date research evidence outweighed statements based on SSA's experience of running the program.

Research findings also played a part in the subsequent revision of the mental impairment listing. The National Institute of Mental Health, as well as the National Institute on Alcoholism and Alcohol Abuse and the National Institute on Drug Abuse, were invited to send their representatives to the special work group charged with doing the job. Participants took care to bring all relevant research evidence into the discussions. The psychiatric nomenclature of the *Diagnostic and Statistical Manual of Mental Disorders*—itself a consensus summation of research as of 1980—was the basis of the terminology

of the revised listing. Ultimately, the entire product of these deliberations was the subject of a two-year research contract from SSA to the American Psychiatric Association to evaluate the reliability and assess the validity of the new mental impairment standards.

Although the work group participation and the *Minnesota* testimony were not the first times that psychiatric research and clinical experience played a role in social policy making, their occurrence did introduce new elements into SSA policy making. Further, psychiatric and rehabilitation expert testimony was a factor in the New York lawsuit involving issues similar to the *Minnesota* case. In deciding in the plaintiffs' favor the court relied upon the research evidence to confirm clinical judgments at odds with SSA's determinations; the court was especially concerned that bureaucracy not override professional medical judgment (Rubenstein, Gattozzi, and Goldman 1988).

It seems fair to conclude, then, that research did make a difference in the mental disability issues of the early 1980s. And research continues to make a difference. SSA has used its expanding authority to conduct and evaluate demonstration programs to focus on the problems of the mentally impaired. Furthermore, it seems likely that SSA will review the findings and recommendations of the American Psychiatric Association (1987) study in its deliberations over the reissue of the mental impairment listings. SSA's failure, however, to issue mental impairment standards for disability in children, developed by a work-group process similar to the one employed for adult disability, suggests backsliding. The agency has the opportunity to continue to be responsive to the views of outside mental health advocates and researchers or to retreat, again, into insularism.

Although these specific instances do not constitute a trend, they are noticeable exceptions to the general case wherein psychiatric research findings take a backseat to political considerations in social policy-making councils (S.S. Sharfstein, personal communication, 1987). The preference in social policy making for politics over scientific technologies will not disappear, nor would that necessarily be a good thing (S. Jencks, personal communication, 1987). Current knowledge is incomplete. Specific research findings often are difficult to translate into broad policy. Science provides only limited answers. The public needs its voice. Taxpayers have strong opinions about how their money is spent; advocates have strong opinions about how it is *not* spent. But a leavening of research and clinical data added to the making of

mental health policy is to be applauded. In light of the story told here, there is reason to hope that it will be included more consistently in the future.

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