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FAS and the Social Security Disability Process: Navigating the System

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Introduction

For some people with Fetal Alcohol Syndrome, there may come a time when they consider applying to the Social Security Administration for disability benefits. The decision to apply or not, and the impacts of that decision on a person with FAS, their loved ones and medical providers, can have long-ranging positive and negative effects. The decision to apply for Social Security disability benefits involves many legal, social, medical, vocational and psychological considerations. Once a decision to apply for such benefits is made, the claimant faces seemingly insurmountable barriers of bureaucracy, delay, and medical and legal processing, which can defeat an otherwise entitled claimant. With the belief that knowledge is power, the following chapter is written for those with FAS, as well as their friends, relatives, counselors, and other health care providers. Armed with an understanding of the standards of disability to be applied to any claim for benefits, as well as an understanding of the bureaucratic process that must be negotiated, it is my hope that those involved, either directly or indirectly, in the process of applying for and assessing disabilities will be better able to insure that the Social Security Administration makes a fair and informed assessment of *all* information relevant to the claimant's impairments.

Two cautionary points: first, simply applying for disability benefits with the Social Security Administration does *not* entitle a person to those benefits. As will be described below, a very rigid and restrictive definition of "disability" is applied by the Social Security Administration. A claimant's financial need, the untherapeutic nature of the evaluative process, the "social/political" wisdom of Social Security's disability system play *no* role in determining whether or not a claim for benefits has met the legal standards of disability. Second, although claimants must show that their disabilities render them unable to perform any kind of work for a continuous period of twelve months, a finding of disability by the Social

Security Administration should not be seen by those with FAS or any other disability as forever branding these people unable to work for the rest of their lives.

Under current regulations, the Social Security Administration reviews each case every three years. Nobody applying for these benefits is served by defining their existence or their view of themselves by the opinions reached by the Social Security Administration, whether benefits are awarded or not. In most cases, claimants applying for disability benefits are best served by living their lives, pursuing their treatment and sticking to their goals, independent of the outcome of any claim for disability benefits. In my eighteen years as a lawyer representing claimants before the Social Security Administration, I can not think of any client whom I helped to obtain his or her disability benefits who felt, by our joint efforts, that his or her goals in life finally had been achieved. As I frequently tell my clients, Social Security disability benefits are rarely a goal in themselves, but benefits can be a critically important tool that can serve a client well while he/she works with friends, family and health care providers in an ongoing struggle with his/her disability. The income provided by the Social Security Administration through its disability programs is never as much as one might make if one could work full-time, and the medical care provided usually does not cover all of the claimant's medical needs. However, through the assistance of Social Security's financial support and the medical coverage, many claimants are given vitally important support which allows them to strive to improve their own disabilities. Without this support, such continuing struggles might be beyond their means.

Basic Facts of the Social Security Disability System

The Social Security Administration, a federal agency under the umbrella of the Department of Health and Human Services, administers two disability programs. When people apply for "disability benefits" with the Social Security Administration, they may be encouraged to apply for benefits under both programs. Realizing the differences and similarities of these two programs is essential to a thorough understanding of how this "system" works, and of what benefits the applicant may be entitled to receive.

Title II Disability Insurance Benefits

The first disability program administered by the Social Security Administration is called "Social Security Disability Insurance

Benefits" (also known as SSDI, Title II, "Disability" or even "SSA"). This program, which I will refer to as "Title II," is, as its formal title implies, a disability insurance benefit. Like an insurance policy, claimants have to show that they are both "disabled" *and* have "paid their premiums" and gained their insurance coverage. The way "premiums" are paid is by the individual having a work history and paying Federal Insurance Contributions Act (FICA) taxes. Claimants must show that, from the date they first became disabled, they have paid into the Social Security system by working and earning approximately \$500 per quarter in five out of the last ten years (twenty out of the last forty "work quarters"). Thus, what date a claimant asserts he or she became disabled is a critical determination which may have an important impact on whether the client is found eligible for Title II benefits, regardless of whether the client is now disabled. Title II disability benefits based on a parent's work history can also be awarded to people who have no work histories themselves but who have been continuously disabled prior to reaching age 22. For such people to receive Title II benefits, they must show that one of their parents had a work history, paid into the Social Security system and is either aged, blind, disabled, retired, or deceased.

Another feature of Social Security Title II disability benefits is that income and resources are not directly relevant to a claimant's eligibility for benefits. This is not to say that a person who is gainfully working can expect to receive Social Security disability benefits. However, if a person has an inheritance or investment income, not directly related to working, it should have no effect on the individual's eligibility for Social Security disability benefits.

If an applicant is found eligible for Title II disability benefits, that individual also will be eligible to receive Medicare insurance. However, Medicare insurance is payable only after two years from the date the claimant is found eligible to receive Title II monthly benefits. In addition, monthly premiums of approximately \$43.80 currently are taken out of the claimant's Title II monthly disability check to pay for the Medicare coverage. Medicare does not pay for most outpatient medications.

The amount of monthly benefits payable to the claimant is based on the level of past earnings, the frequency of those earnings, and how recently those earnings were received. Without consulting Social Security's computer record of earnings, it is virtually impossible to tell what monthly benefit level an applicant might receive. In addition, retroactive benefits can be awarded up to one year prior to the date of application, if the claimant can show that he or she was

disabled at that time. With the long delays with the application process, it is not uncommon to have a substantial back award in a given case.

Supplemental Security Income

The second disability program administered by the Social Security Administration is called "Supplemental Security Income Benefits." This program is also known as "Title XVI," Supplemental Security Income or "SSI." It is important to distinguish this program from the Social Security Disability Insurance Benefit Title II program. SSI is not like an insurance policy. Indeed, while claimants for SSI have to prove their disability by the same standard used in the Title II program, SSI applicants also must prove that they are "poor." SSI is similar to the public assistance disability program, in which the claimant must not have significant non-exempt resources or income. As a rule of thumb, a claimant for SSI may not have more \$2,000 in non-exempt resources as an individual, or \$3,000 in non-exempt resources as a married couple.

The original concept of the SSI program was to "supplement" the income of those disabled Title II recipients whose earnings records and resulting disability benefit payments were low. In the State of Washington, the current maximum benefit level paid on SSI alone is \$512. Throughout the United States, the various states can voluntarily choose to supplement the SSI benefit level. Some states contribute several hundred dollars in matching funds to those provided by the Federal government. In those states, such as California, the benefit level on SSI is higher than is the level in those states that do not contribute.

With the receipt of SSI disability benefits comes a medical coverage — Medicaid. If an individual receives even a dollar of SSI benefits, that eligibility for one dollar of SSI benefits entitles a recipient to coverage by the Medicaid program.

Unlike the Social Security Disability Title II program, retroactive benefits can be paid only to the date the claimant first applies for SSI benefits. Retroactive benefits prior to the date of application on an SSI claim are not available.

Definition of Disability

At the heart of both Title II and Title XVI disability programs is the unique definition of "disability." Social Security's concept of disability is difficult to comprehend until one realizes that, although they use a word that is found in the English language and is pronounced like the English word "disability," Social Security's use of

the term "disability" can best be understood as a unique foreign language. Only when claimants, their family and friends, and their health care providers understand Social Security's definition of "disability" can they seek to provide relevant information that will be essential to documenting a claimant's limitations.

Social Security's defines "disability" as follows:

... the inability to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment which can be expected to result in death or which has lasted or can be expected to last a continuous period of no less than twelve months.

This definition of disability is not necessarily the same one used by state welfare disability programs, private disability insurance programs, the Americans with Disabilities Act, or other programs. It is its own definition, unique to the Social Security Administration, and it is the only definition applicable in a claim for disability benefits with this agency. The determination of whether or not a person is disabled under this definition is a legal determination. It is based on many factors, including medical evidence, age, education, and vocational factors. The fact that the claimant has been found disabled for another program, such as Labor and Industries, or a private insurance policy, does not prove that the claimant is "disabled" as defined by the Social Security Administration.

Put simply, and in possibly a slightly overstated fashion, the "disability" definition requires that a claimant applying for disability benefits must show that his or her physical and/or psychological impairments produce symptoms (which are reasonably related to their documented diagnosis) that preclude the individual from doing any job that exists in significant numbers in the national economy. It does not matter whether or not the claimant applying for disability benefits has ever done this work before. Also irrelevant are whether or not the claimant would like to do this work, whether or not the job would pay the claimant sufficient funds on which to live, or whether or not the claimant actually would get hired in today's job market. Simply put, it must be the medical problems and their adequately documented symptoms which preclude the claimant from doing all jobs.

However, it should be remembered that "substantial gainful activity" is based on a concept of full-time work. The fact that a person can work at a part-time job does not, in itself, preclude a finding of disability. Thus, consideration must be given to whether or not a

claimant would be able to do full-time work, averaging between six and eight hours a day, five days a week. Threshold questions of stamina, reliability, and ability to handle the reasonable expectations and demands of any employer always should be considered.

Because the determination of disability is a complex legal decision, to be made by the Social Security Administration, a brief declaration by a health care provider that the claimant is "totally disabled" is neither a competent legal nor medical opinion. That same conclusion thoroughly documented by the medical findings and assessment of symptoms, however, could go a long way toward proving such a conclusion. The clinical observations and professional medical assessments can be clarified best by the claimant's medical providers.

A claimant also can be found eligible for disability benefits if he/she meets the criteria listed for specific medical conditions in the "Listing of Impairments" of the Code of Federal Regulations (CFR). In the Appendix to this chapter, I have attached the part of the CFR that lists the criteria for "Organic Mental Disorder," the listing most likely to be relevant to FAS. Most people who are found eligible for disability benefits do not meet these more restrictive criteria. If a claimant's medical condition and accompanying symptoms can be said to "meet or equal" a described "listed" impairment, regulations provide that such an individual will be found disabled regardless of their age, education and work experience. Because these criteria were based on the *Diagnostic and Statistical Manual of Mental Disorders, (Third Edition)* (DSM-III), the diagnostic tools currently being employed by the Social Security Administration are somewhat out of date. (There is now a fourth edition of DSM, known as DSM-IV.) However, as the criteria that are employed in assessing disability claims are based on DSM-III, it is important that the medical providers be able to provide information using the terminology of the DSM-III, rather than the more current DSM-IV.

The Application/Administrative Process

Initial Application and Reconsideration

The process employed by Social Security in evaluating a claim for disability benefits, whether it is a Title II or Title XVI claim, is the same. It can be best thought of as the process of climbing a ladder. Each rung up the ladder must be taken in order, with no rung being skipped. Jumping off the ladder after receiving a denial notice and starting over by reapplying will never get the claimant to the top of the ladder, where, by this analogy, benefits are awarded. Instead of

reapplying, the applicant can climb to the next rung only by appealing the previous denial.

The first rung of the administrative process is called the Initial Application. All applications are made in writing, although frequently the application information is taken over the phone and a final "hard copy" is sent to the claimant for signature. In the numerous papers that must be completed in the initial application, the claimant must be bluntly and graphically honest about all the medical problems and must not be embarrassed to describe, in cold, hard details, all of the limitations his or her symptoms impose upon all aspects of a work setting, and in his or her daily life. The application for disability benefits is not a job interview, where it is common to minimize the negatives and glorify the positives. Only if all medical sources are identified, and all diagnoses and symptoms are bluntly and graphically described, can the claimant hope that the Social Security Administration will understand the limitations arising from the claimant's medical and/or psychological problems. The more detailed the information regarding the name, address and telephone number of medical providers, the greater will be the chances that Social Security Administration will locate these providers and obtain the necessary medical information which will prove the claimant's disability.

Once all of the paperwork is completed on the application, the actual papers are sent to a state agency called the "Disability Determination Service" (DDS). DDS gathers and assesses all medical information to determine whether or not the standards of disability have been met. Once a decision is made by DDS, a written "Initial Determination" will be issued. Usually captioned "Social Security Notice" or "Supplemental Social Security Income Notice," these written decisions will advise the claimant if benefits have been awarded. Assuming, for purposes of this article, that such notices deny the claim, the claimant has sixty days to exercise his/her right to climb to the next rung of the application ladder. Within sixty days, the claimant must request a "Reconsideration." This may be done by phone, but the claimant should assume the worst, and make sure that all such requests are done in writing and actually received by the Social Security Administration. It is a useful strategy for the claimant to photocopy and keep in an orderly fashion all papers given to the Social Security Administration.

At the Reconsideration level, a second look at the claim for disability benefits is made by a different person at DDS. If a claimant fails to make the "Request for Reconsideration" within sixty days of the date they received the Initial Determination, his or her claim will

be denied for failure to pursue the claim in a timely fashion. *Always appeal an unfavorable decision well before the expiration of the sixty days.* If the claimant has seen new medical providers, or if additional medical records can be obtained to support the claim for benefits, those records should be described in the papers filled out by the claimant in a Request for Reconsideration. Claimants should also contact their medical providers to make sure that all records are provided which document their disabilities.

A written notice, similar to the first notice, but captioned "Notice of Reconsideration," ultimately will be sent, advising the claimant if his or her benefits have been approved or denied. Once again, to protest an unfavorable decision at this level, the claimant must file a protest within sixty days. At this next step, a written "Request for Hearing" should be filed within sixty days with the local Social Security office.

Administrative Hearing

If a claimant applying for disability benefits has been denied twice, the next stage of the appeals process will be an administrative hearing before a Social Security administrative law judge. While informal, and not similar to the popular images of trials in *Perry Mason* or *People's Court*, the administrative hearing can be quite intimidating. It is likely the first time that the claimant will be face-to-face with the individual making the decision in his or her case. Specific facts and information, relating to both the medical situation and the procedural history, may be centrally important, but this may not be understood by the claimant. It is common to find that the Social Security Administration has called medical and/or vocational experts who might testify and express opinions that contradict those of the claimant or even the claimant's treating physician. Vocational experts testify to hypothetical questions and might express their opinion that, despite the claimant's impairments, such an individual could reasonably be expected to do a variety of jobs.

The hearing gives claimants the best opportunity to present their own testimony and that of parents, spouses, friends and medical providers, to document both the diagnosis and the pervasive nature of the symptoms which are the basis of the claimant's disability. While the medical providers may be able to testify about their assessment as to diagnosis and the symptoms which lead to that diagnosis, non-medical "lay" witnesses, such as friends, relatives, or counselors, also can play critical roles. Such lay witnesses can act as the eyes and ears for the administrative law judge, to insure that the judge understands how the medically diagnosed conditions actually

impact on the claimant's daily life. One way of understanding the role that lay witnesses can play is to think of such friends or relatives as video cameras, who have recorded the sights and sounds of the symptoms of the claimant's impairments. At the hearing, such witnesses can "play back," in graphic and bluntly honest detail, all of the limitations they have observed which, in any way, impact on the claimant's daily life and ability to work.

Specifically with respect to FAS, the wide range of the claimant's symptoms should be fully described by the witnesses at the hearing. The claimant's limitations in handling stress, maintaining stamina in work production or pace, the claimant's reactions to expectations of production, as well as limitations of concentration should be described, if relevant. The manifestations of cognitive impairment and confusion, memory problems, limitations of verbal communication, comprehension, limitations in response to stimulus, impulsivity, poor judgment, as well as any other symptoms which can be documented should be graphically and bluntly described.

The presentation of live medical testimony at the hearing from the claimant's doctors can be quite helpful, but is often difficult to arrange, if for no other reason than the doctors' busy schedule. From the very start of the filing of a claim for disability benefits, supportive health care providers should be encouraged to submit copies of all medical records, as well as a detailed narrative report summarizing their findings. Test results, counseling notes, school records, as well as other records which may have developed over the years, might well be compelling evidence to document the disability based on a diagnosis of FAS. Remember that it is the symptoms of a diagnosed condition, and not the mere diagnosis, that determine the severity of a person's limitations and any eligibility for disability benefits.

Decisions as to the strategy of presenting information at a hearing need to be made in advance. It is not uncommon for the claimant to excuse himself or herself while witnesses testify about the nature and severity of the claimant's impairments. Considerations need to be made as to the therapeutic impact of the blunt and graphic testimony from friends or relatives who focus solely on the negative limitations imposed by the claimant's impairments.

Legal Representation

Legal representation at the administrative hearing frequently is critical to insuring the presentation of the strongest possible case. While Social Security disability law is not one generally practiced by most lawyers, in most large cities there are experienced practitioners who regularly appear before the Social Security Administration at

disability hearings. Most experienced practitioners take such cases on a "contingency basis." This means that the lawyer seeks no payment for his or her fee unless he or she is successful in gaining the claimant his or her benefits. Usually a lawyer's retainer agreement provides that the lawyer is to be paid 25% of the retroactive award that is paid in a successful case with the fee not to exceed \$4,000. All attorney's fees to be charged must be approved in writing by the Social Security Administration, even if both the lawyer and the client agree to the fee. If a claimant seeking legal representation is unable to locate a lawyer in his or her area, the National Organization of Social Security Claimants' Representatives (NOSSCR), located at 6 Prospect Street, Midland Park, New Jersey 07432 (1-800-431-2804), has a free nationwide referral service.

Posthearing Appeals

In most cases, the administrative law judge will not announce his or her decision at the end of the hearing, but will take the case "under advisement" and issue a written decision several weeks after the hearing. If the decision is unfavorable, further appeals may be taken, within sixty days, to the last administrative level, called the Appeals Council. This final branch of the Social Security Administration is located in Falls Church, Virginia, and the review is done solely on the evidence presented at the administrative hearing, along with any written legal arguments that are submitted to the Appeals Council.

If the case is again rejected by the Appeals Council, the claimant has sixty days to file a formal appeal in federal district court. Most lawyers are hesitant to take on a new case for the first time after it has been denied by the Appeals Council because the lawyer has had no input into the preparation or presentation of the case to that point. Any federal court appeal will be limited to the records of the case up to that point.

Conclusion

The process of applying for Social Security disability benefits can be an overwhelming and prolonged effort that can appear insurmountable. Many of the symptoms of FAS make climbing this mountain far more difficult for those with FAS than it would be for the average, unimpaired person. The best opportunity to present a comprehensive claim for benefits can be achieved only through the team efforts of the claimant, family and friends, health care providers, and, at times, the claimant's legal representative. Because

the Social Security Administration has no specific FAS criteria of disability, each claim necessarily will include efforts to educate the Social Security Administration and, if necessary, the administrative law judge, as to the nature of FAS in general, and, more importantly to, the specific manifestations of the symptoms in the given claim for benefits. With perseverance, determination, and attention to the details of the process, the seemingly insurmountable mountain called Social Security disability can be climbed.

Appendix 1

Code of Federal Regulations, Volume 20, Chapter III, Part 404, Subpart P (4-1-95 Edition)

12.01 Category of Impairments — Mental

12.02 *Organic Mental Disorders*: Psychological or behavioral abnormalities associated with a dysfunction of the brain. History and physical examination or laboratory tests demonstrate the presence of a specific organic factor judged to be etiologically related to the abnormal mental state and loss of previously acquired functional abilities.

The required level of severity for these disorders is met when the requirements in both A and B are satisfied.

A. Demonstration of a loss of specific cognitive abilities or affective changes and the medically documented persistence of at least one of the following:

1. Disorientation of time and place; or
2. Memory impairment, either short-term (inability to learn new information), intermediate, or long-term (inability to remember information that was known sometime in the past); or
3. Perceptual or thinking disturbances (e.g., hallucinations, delusions); or
4. Change in personality; or
5. Disturbance in mood; or
6. Emotional lability (e.g., explosive temper outbursts, sudden crying, etc.) and impairment in impulse control; or
7. Loss of measured intellectual ability of at least 15 IQ points from premorbid levels or overall impairment index clearly within the severely impaired range on neuropsychological testing, e.g., the Luria-Nebraska, Halstead-Reitan, etc.;

AND

B. Resulting in at least two of the following:

1. Marked restriction of activities of daily living; or
2. Marked difficulties in maintaining social functioning; or

3. Deficiencies of concentration, persistence or pace resulting in frequent failure to complete tasks in a timely manner (in work settings or elsewhere); or
4. Repeated episodes of deterioration or decompensation in work or work-like settings which cause the individual to withdraw from that situation or to experience exacerbation of signs and symptoms (which may include deterioration of adaptive behaviors).