The Little Book of Advocacy

A Helping Hand

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Foreword

This book was written by the Office of Disability Concerns and carefully reviewed by the following agencies: the Oklahoma Department of Human Services, the Oklahoma Department of Rehabilitation Services, the Oklahoma Health Care Authority, the Oklahoma State Department of Education and the Social Security Administration. I am grateful to all those who have helped make this publication possible. I hope it will assist individuals with disabilities in getting their needs met.

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Introduction

The Office of Disability Concerns fields many questions from Oklahomans just like you who are interested in services for themselves or a family member or friend. Many people are unaware of resources existing now within the state to assist them in meeting their needs.

Many people have qualified for some type of program serving people with disabilities, but they have little understanding of how that program works. Lack of understanding of the program limits their utilization of that program causing frustration.

Sometimes people call the Office of Disability Concerns with a need which appears cannot be filled within the existing service-delivery system. People would like social services to address their needs, but they have little idea how to advocate. They do not know who to talk to nor how to present their concerns.

The purpose of this book is to assist people with disabilities to get their needs met. The book is divided into two sections.

The first section of this book will address simple, effective things which anybody can do to advocate for their needs. The last section of the book will discuss how to appeal a written decision within some programs which people with disabilities utilize most frequently. The last section will also provide some information on the structure of these programs which will help navigation within that system.

The goal in writing this book is to give some insights which will make advocacy easier. We have shared the experiences of many

Oklahomans who are just like you. People with disabilities have been our trainer for many years now.

People with disabilities often have high expectations. They also many times have multiple needs. Unfortunately high needs and high expectations do not always fit within the reality of existing services. This is the reason why advocacy is such an important concept in the community of people with disabilities.

There are advocacy organizations in Oklahoma. However as an individual, you are going to have to be your own advocate in many situations. This is reality. This book describes how some Oklahomans have successfully advocated to get their needs met.

We’ve all experienced roadblocks to getting our needs met. You may learn to present your case in such a way as to navigate through the roadblock you are experiencing, or you may learn an alternate route which will bypass the roadblock altogether. Even if you don’t get a direct answer to your concern reading this book, we hope that you will see that other people have identified the same concern, and you are not alone.

Know Your Needs

What does knowing your needs mean? It means assessing how disability has affected your everyday life. You say you are able to walk. How far can you walk without assistance? How long can you stand without having to sit down? If you have a mental health disability, can you work part time? Can you work full time? Do you feel that your symptoms are controlled with counseling, medication, or both? Will you need assistance in getting back into the work force?

A person with a cognitive disorder may consider if they are able to handle money. Does a person with a disability feel they need a legal guardian in some area of their lives? If the answer to that question is yes, what area do they feel they will need help in?

If you are a person with a visual impairment, do you feel you are a good candidate to learn Braille? Can you access the public transportation system? People with disabilities must review every aspect of their life.

What do they want? What do they need from other people to build a life? People are not used to thinking about this, but it is very important to know your needs when you approach the service delivery system.

People ask, “Why is it important to know my needs? I thought the professionals were supposed to know all that and figure out how they could help me.”

If people with disabilities wait for the professionals to tell them what they need, they are shortchanging themselves. Social services in Oklahoma are based on identifying the needs of people they are designed to serve. If people do not self-disclose their needs, their services will never be adequate.

Social services today are needs driven. The service provider does not offer the public physical therapy, occupational therapy, job coach services, counseling, and architectural modifications asking which they would like.

The service-delivery system is not a cafeteria where people walk through and say, “I’ll take some of the green beans, mashed potatoes and gravy.” The services prescribed for an individual with disabilities are based on the identified needs of that individual.

The service-delivery system is not a cafeteria where people walk through and say, “I’ll take some of the green beans, mashed potatoes and gravy.”

Now, how does a person describe their needs? Do they tell a service provider that they need physical therapy four times a week? The answer to that question is “No”. Tell the service provider that it takes you twenty minutes to walk from your front door to your car. Ask for assistance in improving your walking. It is up to the service provider to decide what services they can offer to meet your needs.

If you are a person who has had a stroke and have lost your ability to speak, write down on a pad that you need assistance in communication. When you identify your need, the service provider decides how they can help you meet that need.

This is the way the system works. People have a real responsibility in identifying their needs. If they wait for someone else to decide what their needs are, they run the risk of not getting their needs met or only partially getting those needs met.

People who do not know this become angry and frustrated, but this frustration is not necessary. People have the key to unlock the service-delivery system. The serious work in self-assessment is time well spent. No one else can do that.

Ask for What You Need

Why is it so hard to ask for what we need? For many people with disabilities, it is hard to ask someone else for assistance. Even when they have done the hard work of identifying their needs, it is still hard to approach someone in the service-delivery system with a specific request.

Maybe it is an issue of pride. People fear giving power to another person and risking that person saying “no” to something which is very important. But asking for what you need has nothing to do with what the other person does. It has everything to do with what you do.

Asking for what we need is difficult because in doing so we expose our vulnerabilities. It is difficult to approach a complete stranger to share that you have a problem with incontinence. It is difficult to admit that you cannot sign your name after having had a stroke. For the person who has gotten a lot of their self esteem from their work, it is difficult to discuss with another person that they cannot continue to work and will need public assistance to meet their financial needs.

Yes, it is difficult, but do it anyway. One person spent a good part of their adult life expecting other people to meet their needs. Those needs seemed so obvious to the person with the disability. This person felt the other people around were cruel and uncaring because they made no effort to help. Ask for what you need. Other people cannot and will not read your mind. They have enough trouble reading their own minds and learning to ask for what they need.

Let’s discuss this vulnerability which people are afraid to expose. What is the worst that the other person representing their social program can do if people dare to ask for what they need? They can say “no”. That is the biggie, isn’t it? “No” comes in many forms. You are not eligible for our program. We do not provide that type of service. You are too old. You are too young. Is that all right?

Sometimes a particular program cannot help. Ask the program representative to provide you the written policy highlighting what applies to you, but it is still all right if the agency is not able to provide the service you need. You have identified your specific need, and you have been courageous to ask that someone or some program assist you.

Before you hang up the phone, ask that program representative if they know of another program which could assist you. Many times people who work in social services are familiar with other agencies and programs. An agency which develops jobs for people with disabilities may not be able to assist you in meeting your residential needs, but they may indeed know of sister agencies which provide residential services.

Asking for what you need is operating in the present. Before your disability you may have had a highly responsible job, and you helped to support your spouse and children. But your disability has challenged you to a new reality.

It is all right for a person to grieve that they are not able to do all the things they used to do, but it will not help to get stuck in grief. Move to the present and accept your needs. When you have accepted those needs, you will be able to ask for help.

Now what about that other person or agency who has verified in writing that they are not able to help you? Ask another person. Ask another organization to meet your needs. Your job is to get those needs addressed in whatever way possible.

Agency A may tell you they can meet part of the needs you have expressed but not all of them. Someday in social services we may have one huge market which will have the capacity to meet all needs, but that does not exist today.

You may well have to approach more than one person in your efforts, but that is all right. You have asked for what you need, and you will continue to ask for what you need until your concerns are addressed.

Know What You Are Feeling

“Be true to yourself” is a wise saying. One thing people need to do in self-advocacy is to become aware of their feelings. Are you angry about what has happened? Are you afraid of what may happen to others as a result of a certain policy? How do you feel about the staff member who has given you the decision you disagree with? How do you feel about the agency that has made a decision you disagree with?

Your feelings may be based in reality and then again they may not. You say, “I have a right to my feelings,” and certainly you do. But your feelings may or may not be justified objectively in what is happening. It is important you identify this. You may question the motive of why the decision was made that you disagree with. Seek the facts on why decisions were made before you act.

A person called the Office of Disability Concerns and explained that a group of people representing an agency had removed a family member from their home. The person explained they felt these people had made the recommendation because of a complaint lodged against them earlier.

Was there any proof that the complaints had resulted in an unfavorable decision? No, there was none. Unsubstantiated feelings about the agency are not beneficial in advocating that the decision itself was wrong. Unsubstantiated feelings may be of use in putting the advocate on alert for future behavior which may prove a pattern.

Sometimes people are angry about social services which are being cut off or income which is garnisheed because of an overpayment. People may become angry when a housing voucher is stopped.

The causes for the anger are infinite, but the personal response is similar.

It is important that an advocate be aware how they feel and how strongly they feel about an issue. Anger can serve as energy to propel a person to a resolution of the problem or it can be so intense as to prevent a person from seeing the objective facts of the situation. In this way it becomes an obstacle to achieving the desired result.

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One person called this office in tears. Their administrator had called them the day before and shared his decision that the person was no longer disabled and no longer needed to use the one handicapped parking place at this private, non-profit agency.

Reportedly the person had undergone two surgeries and medical professionals had signed information for the Department of Public Safety to grant a handicapped parking permit for five years. The caller was overcome with emotion. If the caller insisted on the handicapped parking place, they feared the administrator would dismiss them. Something was wrong.

Fear can be immobilizing. People may tolerate a situation which is clearly unsatisfactory beyond reason because of their fear.

Learning to advocate for yourself will help in getting your needs met.

Focus Your Efforts

Good advocates seek to be pro-active by setting priorities for their advocacy. It is overwhelming to look at the service-delivery system today and think about how services for people with disabilities could be improved. This is reason to focus our efforts in order to be more effective.

We may choose an issue which impacts us most directly. We may consider something which enjoys current public scrutiny. It may be good to focus on an issue which affects the largest number of people with disabilities. Out of this maze of possible concerns, it is worthwhile to choose one and focus untiringly on that issue until it is resolved.

One advocate for people with disabilities pointed out that Oklahoma's definition of "developmental disabilities" was too narrow because it referred only to people who had an IQ of 70 or less. This advocate never tired in public meetings of drawing attention to this gap in service.

This person pointed out that developmental disabilities is a broad term which includes all disabilities (both physical and mental) occurring before the age of 21. A person who had a spinal cord injury and used a wheelchair for mobility may indeed be developmentally disabled regardless of IQ.

This advocate’s comments were especially powerful because they were talking about something they personally experienced and impacted the services of people with disabilities across the state.

Within a couple years of persistence, our service-delivery system broadened. We began to serve people who were developmentally disabled with various physical disabilities which were not previously served in our state.

When that issue was addressed, this advocate had another issue for public consideration. It is important to focus energy if the advocate is going to be successful.

Another Oklahoman had an issue which concerns many people in our state. This person had an issue of access. They also had an issue of handicapped parking. These were issues which directly affected this person who had a lift-equipped van and who used a scooter to get around in public.

People listened because they knew this advocate was speaking from experience. If the advocate had chosen an issue which did not affect them, people might not have listened so readily. Focus your efforts on an issue, and follow through over a period of time.

There are many issues out there, but they may not all be issues which concern a particular person. There’s plenty of room out there for many people to advocate. We can choose an issue which we know the most about and have the best chance to be successful.

Identify the Facts

In the process of advocacy, people will encounter other people who have a different opinion about what should be done. People will encounter a public policy which seems to support something they disagree with and which no longer seems to meet the needs of the public. At this point it is useful to identify all the facts that come to bear.

Facts are objective, verifiable things which can be agreed upon by all parties involved. Let's use a hypothetical situation and say a person uses a nebulizer to breathe. This person must have this machine which uses electricity to sustain life. That is a fact. If someone doubts, they may contact the doctor who has made the diagnosis.

The power company sends a notice that the power will be cut off because of failure to pay a large bill. The power will be cut off on a certain day, and there is a letter from the utility to this effect.

There is no doubt that this letter has aroused a great deal of fear. What will happen? Panic sets in. It is important to identify the relevant facts. The finances of the individual are important. The availability of that next Social Security check is important. The help from another family member is important, but there are other facts as well.

Who regulates the utility? Does the resident know someone else who has received a cutoff notice, and what did they do? Does the resident know someone with a generator? Can the individual get a letter from their doctor verifying the need for a nebulizer to breathe?

Facts bring information and shed light. Facts are places where there is widespread agreement. They help to counter the frustration and confusion of conflicting opinions.

Focus on the facts if you are going to successfully advocate your position. If an agency where you receive services has a policy that a grievance must be filed in writing within a certain number of days after a denial of services, that is a fact which must guide your advocacy.

Facts are places where there is widespread agreement. They help to counter the frustration and confusion of conflicting opinions.

Ignoring that fact will result in the failure of your advocacy before it ever has a chance to be presented. It is your responsibility to identify facts which you do not have which are relevant to the situation at hand. Ignorance is no excuse.

Spend some time writing down the facts which you know. Gather facts and information which you do not know which will affect your successful advocacy. To go back to the caller who had a handicapped parking placard, it is important to know how long that placard is valid. The administrator and employer of this person had made the decision that their employee was no longer disabled and had no further need to park in handicapped parking.

The Department of Public Safety issues temporary placards which may be used for six months, and they issue placards which may be used five years. The duration of the placard which our caller had has a direct bearing on the situation in dispute. Know where you stand. Facts provide firm ground.

Learn Policy and Procedure

Policies and procedures are the framework in which resolution of a grievance takes place. All agencies have policies and procedures, and these policies and procedures are public information. If you have a dispute with an agency and you want to advocate for yourself, learn about the policy and procedure of the agency which is applicable to your situation.

You say it's not fair that they make your child share staff. It may not be fair. It may lower the quality of services your child receives, but it is agency policy. Be aware of the policy which is applicable.

Ask that an agency representative send you a copy of the policy with what is pertinent to your situation highlighted. Agencies will not act outside their policy although it may be possible to challenge the policy itself in some circumstances.

Learning policy and procedure is like learning the rules of a game. You may disagree with the rule, but you cannot really challenge it until you become aware of its existence. People complain about administrative decisions all the time without having the slightest awareness of the policies and procedures behind those decisions.

One of the first steps in successful self advocacy is becoming aware. Learn the rules and follow them if you want to challenge the agency on its decision regarding you.

One governing board in Oklahoma offers the public opportunity to speak before the board, but it is necessary that a person get on the agenda to speak before the meeting and that the individual limit their comments. Those are the rules.

The advocate who attempts to speak at the board meeting without being on the agenda will be denied the opportunity. The advocate who is on the agenda but who attempts to speak longer than the time allotted according to policy will be interrupted. It is important to know the policies and procedures.

The Office of Disability Concerns received a letter from an individual who was in state custody expressing that the facility where they lived did not respect their disability in initiating punitive measures against them. They felt the facility had treated them unfairly without regard to their disability.

The agency did indeed have an established grievance procedure involving several steps toward resolving residents’ concerns with progressively higher levels of appeal. Grievance procedures were posted at key communal points in the facility notifying residents how to dispute an issue.

Policy describes the intent of agencies. These are guidelines for agency service delivery. Policies and procedures can be challenged by people with disabilities when they feel these guidelines no longer meet their needs.

One man in Oklahoma with the cooperation of others successfully challenged a state law which he felt was not broad enough to represent his needs. He first got a copy of the original law so he would be thoroughly familiar with it. After this, he contacted the legislator who had authored that law and asked him to sponsor a new bill which was more inclusive for people with disabilities.

During the legislative session, he followed the progress of the bill through the legislature contacting committee chairs as appropriate to convince them to keep the bill alive. The new bill was successful and signed by the Governor; it became the new Oklahoma law replacing an older, more narrowly-defined law.

In order to challenge an existing law or policy, the advocate needs full knowledge of the policy first before they are able to make the desired changes. A lot of other people have to buy into the changes in the process.

Policies may change because advocates have successfully challenged them, but they also change for other reasons. The U.S. Department of Health and Human Services sets poverty guidelines for the forty-eight contiguous states and Alaska and Hawaii. These poverty guidelines are used by a number of programs to determine eligibility standards for the program.

The poverty guidelines are reconsidered annually and almost always are revised upward. Individuals or families of various sizes are enabled to make higher incomes and still qualify as being in poverty as a result of these changes initiated by the government itself.

The same thing is true of the Social Security Administration. At one time, the income that an individual drawing Social Security

Disability Income (SSDI) could earn before being penalized in their Social Security payments was five hundred and forty dollars per month. Four years later that figure was considerably higher.

These changes reflect the fact that Social Security was encouraging individuals with disabilities to return to work by making returning to work more profitable for them. Policies change for whatever reason, and it is important that the successful advocate be aware of those changes.

Contact the Right People

One person called the Office of Disability Concerns on an issue of transportation for people with disabilities. This person had already written letters to representatives of state and federal government. When these government officials were unable to help them, the individual became angry and resentful.

This person lived in a city in Oklahoma which had annexed a great deal of rural land back in the 1960’s. Public transportation was available in the more urban portion of this city, but it was not available in the rural precincts which were, by the way, still in the city limits. This person had a real issue, but this issue was not with state or federal government.

Tell your complete story only when you are reasonably sure that this person can help you.

The issue was with local government. This person began attending city council meetings and getting on the agenda. They supported a new person running for city council from their precinct. This advocate's energy became focused and through this focus was successful in getting public transportation extended to the more rural parts of the city.

To advocate successfully, you have to know the right people to address. You have to know exactly what your issue is and who has the authority to make the changes you want. If you do not know this and attempt to act anyway, you risk the chance of being shuffled from person to person with no progress towards your ultimate goal.

Do you need to speak to the director or to a program administrator? Will speaking to any committee person suffice or do you need to address the chairperson? Who actually has the authority to give you what you want? Most organizations will have an organizational chart which can help you make the decision.

Specify your issue and ask direct questions to help you get to the right person. Many people grow tired of telling their story over and over again only to find they are directed to still another person. Tell your complete story only when you are reasonably sure that this person can help you.

Develop Support for Your Issue

Advocacy can be done by a single individual, but often the individual's cause is strengthened by developing support from other people and other agencies within the community. One person called this office reporting that they were frustrated in years of corresponding with a person in authority about an issue which was important to them.

This person had collected a series of letters with letterhead from the agency they felt could solve their concern. These letters were signed by a duly-authorized employee of that agency. The letters were good documentation that this person was actively involved in getting their concern addressed. Unfortunately, the concern was not getting addressed although it was generating a lot of correspondence.

This advocate contacted a local organization which had a similar interest. When representatives of this organization became aware of the problem, they espoused the issue wholeheartedly. The agency contacted the person in authority asking that the issue be addressed.

The results of this effort were successful and the original advocate achieved their purpose. Working alone they had not been successful, but working in conjunction with an agency brought the desired results.

One advocate located other people who had a similar disability and faced a similar concern locally. With this added support, they were able to convince the authorities to expand the service system to meet their needs. When the authorities realized that the issue affected more than just one person, they were willing to sit down and talk and eventually do something to meet the needs.

Many people begin advocating for an issue important to them without being aware of already-existing groups who are affected by the same issue in their local area. The person advocating for improved public transportation may contact another organization because they have a natural interest in improving public transportation also.

In the field of disability advocacy, many people are not aware that the federal government recognizes a particular agency in each state with responsibilities of protection and advocacy. This may provide a natural starting place for the beginning advocate to express their concern and ask what efforts have already been made.

Timing and Advocacy

Changes in public policy are made when the general public becomes fully aware of a concern and is ready to address it. An issue brought out before the public is willing to consider it is effort which could better be spent elsewhere. A good example of this is the issue of smoking tobacco products.

There was a time when non-smokers were not aware of the health hazards of second hand smoke, but then came a report from the Surgeon General of the United States which described the health hazards of smoking.

Slowly the work place and public places in this country became smoke free. Smoking became regulated in such a way that in many circumstances, health concerns of people who did not use tobacco products were considered.

Regulation has dramatically changed how smoking is permitted in public. If you have a concern about smoking in a public facility, it is probable you will have the ear of the administrator in charge. You will be heard, and it is probable your concerns will be addressed promptly.

That would not have been the case many years ago before irrefutable medical evidence that smoking was harmful to health. To have gone to a supervisor complaining that a fellow employee's smoke was irritating might have fallen on deaf ears in the past.

The public was not ready to accept that smoking was harmful then. Later the public became more educated on the subject and accepted much stricter regulations on smoking.

Advocacy for banning of smoking in public became more effective after medical evidence began to mount and the public became aware. Successful advocacy is promoted by good timing. It is a harder struggle to promote change before the information and supporting facts are widely available.

When controversy still exists on the desirability of a set of actions, advocacy will be slowed. Just because you have a legitimate issue does not mean that you will be heard immediately.

Many people rush into an issue only to be discouraged that others do not agree with the same point of view. Discouragement may lead to a feeling of failure.

If you find yourself advocating strongly for a certain course of action and sense that the timing is not quite right yet for your issue, this does not mean that you should give the issue up entirely. It only means that you should reassess your strategies and benchmarks to achieve your goals.

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Persistence

If you really believe in something, you must persist in your efforts to have success. One woman called outlining how her repeated phone calls to a state agency had finally won the results she sought. She witnessed that if you follow up on your initial contacts, especially if you have new information, that you will eventually be heard. This person continued to call as she also offered new arguments for pursuing a particular action.

People who have applied for services and have been moved to a waiting list sometimes become discouraged. Waiting lists test patience and level of endurance. Certainly waiting lists can be an obstacle to getting what people want and need, but they need not block getting needs met forever.

If you are applying for some kind of services for people with disabilities where a waiting list is involved, send your written application for services. Then follow up that application in about two weeks asking if the agency has received your application.

You would be surprised at the number of times an application may fail to reach its destination for whatever reason. (Be sure to have a copy of your original application to send back to the agency in case they have not received your original.)

Let’s presume that the agency has received your application. They have confirmed that they did indeed receive your application and can even tell you the date it was stamped into the office. Ask that employee if they would mind if you called back to find out where you are on the waiting list.

The answer to this question will most likely be, “No, we would not mind.” You are only asking for information.

Follow up your initial call in a few months with an inquiry of where you are presently on the waiting list. Ask the employee that you talk with and has pulled your application to mark on that application that you called on that particular date asking about your position on the waiting list.

Whoever reviews your application will see that you have called three times over the last year asking about your original application and your number on the waiting list. This shows someone that you are still interested in services and that you are willing to invest some of your time in getting those needed services.

Persistence is important in self advocacy. In your persistence it is also important not to become a nuisance. In the original example, it was suggested to call in a couple weeks to see if the agency had received your application. This showed the advocate had a legitimate interest.

But what if the advocate had called every two weeks for six months asking their position on the waiting list? Too much of a good thing can be counterproductive. Twelve phone calls in six months become time-consuming to the employee who is taking the calls and has many other people to serve.

Legitimate efforts begin to be interpreted as pressure and set up an adversarial atmosphere with the agency concerned. There is a difference between persistence and being a nuisance.

Know What Motivates the Person or Agency You Are Asking

A woman needed one hundred and twenty dollars worth of ostomy supplies and said to an agency that it would cost them less to give her this than for her to develop a rash and have to go to the emergency room. An emergency room visit could cost many times the cost of prevention.

Financial considerations motivated the provider agency to give her what she needed. Financial considerations are real to social-service agencies which are strapped for funds. Show those agencies that it will cost them less to give you what you need. Your position demonstrates that there is something in your proposal for the agency as well as for yourself.

In years past, advocates have argued for services for people with developmental disabilities in the community rather than services in an institution. They have come to the table armed with actual studies which verify that the cost is less and that the community setting is more appropriate. This is a very powerful position that serving people in the community is the direction to go. Administrators listen.

Compliance with federal and state law also motivates people and agencies to meet human needs. This is not to advise the advocate to threaten legal measures. It concerns being familiar with the advocate’s options guaranteed by law and sharing that information in places where it is applicable.

A law office called regarding interpreter services for their client. This law office did not know that the Americans with Disabilities Act of 1990 (ADA) specified that places which served the public had to make their services accessible to people with disabilities.

After a consultation, the law office contacted a local agency which offers interpreter services and paid for this service in order to serve their client who needed that accommodation.

There are many state and federal laws which govern how services to people with disabilities must be administered. The Americans with Disabilities Act of 1990 is the federal law guaranteeing civil rights to all qualified people with disabilities.

The Individuals with Disabilities Education Act (IDEA) governs how schools provide education to their students who have disabilities. The Older Americans Act deals with mobile meals programs across the United States. The Rehabilitation Act of 1973 as amended deals with vocational rehabilitation services across the country.

It strengthens the advocate's position if they know about legislation that impacts their issue. They can be more successful in getting their needs met. The agencies and service providers are impacted by such laws in how they deliver services.

Maintain a Record of Your Efforts

People often call this office with concerns about application for Social Security disability. Social Security is a major concern for people with disabilities, especially if their ability to earn a living has been compromised by their disability.

If a person is not approved for disability payments on their first application, that person may spend some time in the appeals process. If a person is approved for Social Security disability payments on their initial application, that approval may still take considerable time.

How can anyone remember all of the calls they have made concerning their application to any social service agency in this period of time? This is where maintaining a record is so important.

People applying for any program may keep a folder labeled with the program they are attempting to access. In this folder they may put anything which is related to this effort in this one central place where it can be accessed easily.

One of the first things you may want to maintain is a phone log regarding your advocacy efforts. In that phone log record 1) who you spoke to 2) when you spoke to that person 3) who that person represents and 4) a very brief summary of the conversation. You cannot imagine how useful this information becomes to you six months down the line.

Your phone log will remind you when it is appropriate to make a follow-up call to a certain individual. To think you will remember the gist of a conversation with one particular person a month from now—even two weeks from now—is unrealistic.

That record you keep on your advocacy efforts will be invaluable as you persist. The people you contact will be impressed as you remind them of the last time you spoke with them and what was discussed. They may be more inclined to respond favorably to your requests if they perceive you as an individual who is organized and efficient.

What other things can be included in a folder? Place a copy of your original application in that folder. If for some reason your application was <u>not</u> received, you have a copy.

Keep all correspondence which you receive regarding your application in the folder. Make a copy of any correspondence you send regarding your application for services and keep this in the folder as well. Anything which documents efforts to get services is good to have. Your folder will keep you up to date on communication you have made to get your needs met.

Your records may take many forms depending on what you are advocating for. For your child who receives special education services in the public school, you may want to keep a copy of the current Individualized Education Plan in a school folder.

Refer to that Individualized Education Plan to ask the special education teacher how your child is progressing. If no progress is being made, that is a reminder that you may want to ask for another meeting to revise your efforts.

If you are a client of the Department of Rehabilitative Services, you may want to keep a copy of the Individualized Plan of Employment in your folder. The Individual Plan of Employment is an official statement of what services the agency agrees to provide. If the service is not outlined on that plan, the agency has no responsibility to provide it.

Your copy of the plan will spell out clearly what is the responsibility of the agency. The rest may be presumed to be your responsibility.

Monitor Your Attitude

Sometimes it takes awhile in life to become aware of the importance of attitude. It can take even longer to fully realize you have control over your attitude. People who are advocating for a change are often accused of having an inappropriate attitude.

When the discussion revolves around one’s attitude, the original concern is lost. This is a sign that attitude is inappropriate.

One person became angry when an agency offered a differing opinion about what was happening in their case. This person reacted strongly contacting many other people, criticizing, and blaming others over a period of time. Gradually attention became more focused on this person’s attitude. The original issue faded from view.

Consistently maintaining a proper attitude in spite of a difference of opinion can enhance getting your needs met. One person called expressing how they got the needs of their family addressed.

This person was encouraging local officials to respond to the needs of a person with disabilities. The advocate frequently got on the agenda to express the concerns and ways which these concerns could be addressed. Officials appeared to be stalling. Time passed with no progress.

So, this advocate did something that many people would never think of doing. The next board meeting, this advocate showed up with a couple dozen fresh-baked, homemade cookies!

Things began to change. A long-standing policy was altered to meet the needs of a person with disabilities. It appeared that this advocate’s demonstration of a good attitude towards the local officials had a lot to do with the change of policy.

The correctness of the change of policy had to be present first, but sometimes the demonstration of a proper attitude on top of this can be that little extra push that makes all the difference in the world.

It is tempting to take someone else’s decision personally. Just because an individual has a disagreement with one special education team, they can generalize this attitude to all special education teams.

This individual's attitude has turned negative. This person is seeing everything through their disappointment, and that is affecting how other people respond to them.

Monitor your attitude at regular intervals to make sure that you do not let disappointment color your advocacy efforts. It is possible to disagree with a person or a group without having a negative attitude. This will improve your chances at getting what you need.

When the discussion revolves around one's attitude, the original concern is lost.

Be Prepared to Compromise

Sometimes the single-minded focus that advocates maintain to fuel their efforts can actually hinder them. This may seem to contradict what was said earlier about persistence but not necessarily.

Focus and persistence are important in advocating for change, but if that focus and persistence includes an unwillingness to compromise, the advocate shows themselves in an unfavorable light and can endanger the original purpose of their advocacy.

Compromise is a willingness to accept what we want with some qualifications. One Oklahoma family applied for services with the

Developmental Disabilities Services Division (DDSD) of the Oklahoma Department of Human Services. They stated that the only service they wanted for their daughter who had a cognitive impairment was attendant care.

Both parents worked in this family, and their daughter arrived home from school about an hour before any family member. The family felt strongly that their daughter's disability kept her from caring for herself during this interval.

An Intake Case Manager at DDSD received the application for DDSD services and called the family about their concerns. The case manager explained that if attendant care for brief periods was what the family felt they really needed, they could access this service through the Oklahoma Respite Resource Network.

The case manager explained what respite care service was and let the family know how to apply for this service. (The Oklahoma Respite Resource Network is a generic service which offers periods of attendant care when the primary caregiver is unable to provide this care.)

The family had an option—DDSD attendant care services which would take some time to access or attendant care services through the Oklahoma Respite Resource Network which could be accessed more immediately. The family chose the latter service reportedly because they felt the generic service was just as good. The family's needs and the needs of the girl with disabilities were met by an alternate resource.

You may be asked to compromise in many different ways. You are going to be challenged to separate out what is absolutely non-negotiable in your original proposal and what is not.

A person in one small town in Oklahoma wanted to use a golf cart to transport their child with disabilities around the community. City officials said, “All right, we will approve your application to allow golf carts on the streets of this community. However, you have to submit to certain regulations for your benefit and the benefit of other citizens traveling our streets.”

“You must register your vehicle every year just like drivers who use cars or trucks. You must agree to use only residential streets where the speed limit is less than 25 miles per hour. Finally, you must equip your golf cart with turn signals and you must show proof of some kind of insurance.”

This advocate accepted some qualifications to their proposal because they agreed that the community not only had a right to regulate traffic on its streets, but it also had a responsibility to do so. The advocate was willing to compromise, but their compromise did not endanger the integrity of the original intent of the proposal.

When Possible, Plan Ahead

One family moved to Oklahoma after a major natural disaster in another state. They had a young daughter with severe disabilities who had qualified for Medicaid insurance in the state from which they came.

The girl did not qualify for Medicaid in Oklahoma because the family income was too high. This situation presented a medical and financial emergency for the family because of the daughter’s high needs. Even though they had a solid, middle income, the medical expenses which their daughter incurred were great.

Through his call to the Office of Disability Concerns the father of this family learned about the TEFRA (Tax Equity and Fiscal Responsibility Act) program which was new to Oklahoma at the time of his inquiry. TEFRA was a program born in the Oklahoma Health Care Authority to enable children with severe disabilities to be covered under Oklahoma Medicaid insurance in spite of a family income which would normally disqualify the children.

TEFRA involved several steps and required families to re-apply every year, but it offered medical coverage to this child who would probably not be covered otherwise. The family appeared to be very happy that such a program existed in our state.

They contacted the right people and advocated for the needs of their daughter. An unforeseen emergency had destroyed their home, and they were trying their best to assure that their daughter's needs would be met in their new home.

There was no way this family could anticipate the disaster which had befallen the state from which they came. They could only seek the services which they needed as soon as possible after making the move to Oklahoma. They responded responsibly given the scenario they experienced.

Another father called this office a couple of years later with a concern about his son who was thirty-eight years old and had recently been diagnosed with multiple sclerosis. This man recognized that he and his wife were elderly and would not always be able to advocate for their son's needs.

This advocate was researching accessible housing for his son. He was also looking at a need for attendant care for his son in the future. It was true that his son with multiple sclerosis was still working and functioning relatively well, but he knew that multiple sclerosis is a progressive disease which has the capacity to severely impair a person's motor functioning.

This father was planning ahead. He was anticipating future needs based on some pretty sound research he had done on multiple sclerosis and some serious discussions with the neurologist who was seeing his son. His son's needs would most likely only increase with the passage of time, and this father wanted to make sure that a strategy was in place to meet those needs as they appeared.

This same advance planning can benefit you in your advocacy to get your needs met or the needs of family and friends. Accessing programs which serve people with disabilities takes time. Some programs have waiting lists for services. Many programs require a determination of eligibility and the preparation of a service plan to meet the needs of the person with disabilities.

That is why planning ahead is important in your work as an advocate. Where can you go to address the needs of the person you are advocating for? In the case of the father who was looking for accessible housing for his son, what are the standards for accessible housing? How wide should the doorways be? How much weight should a person be able to put safely on a grab bar?

Information gathering is valuable to advocates. It helps them plan for the future before the stress of the present becomes overwhelming. It helps to reduce the time it takes to access the services they need when those needs arise.

You will renew your hope.

Putting It All Together

All of us are advocates. At some time we all attempt to convince another person in authority to consider our views on something which affects our own lives directly or the lives of someone whom we care about. We may not realize that we are advocating, but that is exactly what we are doing.

When we approach someone whom we are trying to convince to do something, it is important to leave that person plenty of room to draw their own conclusions. That person's decision must be their decision—not a decision we are forcing them to make.

The natural tendency for all of us is to present our case with all the subjective emotions which surround that issue which is so important to us. It is not wrong to admit that you have an opinion on the issue. Any advocate worth their salt believes in what they are advocating—many times with a passion. Passion has its place, but it must be tempered with facts.

Advocacy is like playing a game of chess. Each of the different pieces on the board has its own power to move in a particular way. There are rules which govern the game, and a good advocate knows those rules before sitting down with an opponent on the other side of the board. There are rules governing how our advocacy can proceed, and it is well worth our time to learn those rules before we sit down to play the game.

Not knowing the policies and procedures which govern how an agency delivers services is a little like sitting down to that game of chess and not knowing how the pieces move on the board. The opponent who does know how each chess piece moves is at a decided advantage over the person who does not have this information.

Advocacy is a big field and covers many topics. Services for people with disabilities are delivered by a wide variety of public and private agencies. It is worth the time to find out who the right person is to get the job done.

Telling the receptionist in detail the advocate's concern may be a poor usage of time and effort. Finding out from the receptionist who in their agency licenses the local daycare facility may be very useful if we are concerned about the practice of a particular facility in accepting children with disabilities.

It can be very useful to have support for your cause before contacting the person who is able to give you what you are seeking. Many times people feel that they are the only one who is affected by a situation. This is a myth. There are other people out there with the same problem you have.

There are organizations who are already advocating for what you want. It is up to the advocate to find those other people and organizations. Working within a group can be a powerful way to accomplish an objective.

When an advocate identifies the issue and narrows their focus, they do well to prepare to stay with that issue for the long haul. Sometimes you will contact the right person who gives you what you request quickly. Most often this is not the case. You will have to contact many people over a period of time before your voice is heard.

If you have narrowed your focus, contacted the right people, and kept up your efforts for a long while and still have little success, the timing of your issue may be off. The public awareness may not be sufficient to support the change you are seeking. In this case, you may revise your original concern and expect less in the immediate future. This does not mean you give up your concern. It only means you allow more time to accomplish it.

Sometimes advocates are so caught up in their own concern that they do not think about the people they are trying to influence. For an issue to really take off, it must meet the needs of many people—not just our own.

Sometimes we feel so insignificant in the scheme of things. We don’t feel like we can do anything to further our cause but ask the right person. When we get turned down, we feel powerless and are discouraged. There is one thing we can do, and it is helpful. We have control of ourselves. Write down who you talked with and what was said. Record your efforts. Agencies keep files, and so can you.

Stick to issues—not personalities. If that person whom you spent so much time and effort to contact does not provide an answer for you, that does not mean that person is a bad person. It only means that person was not the right person. Be patient. Be positive. You are going to get your needs met. It is only a matter of time.

Become aware of how you feel inside. When you feel you are getting too angry or too negative about a situation, back off for awhile and take care of yourself. Treat yourself to something special. When you feel like it, go back to your efforts and continue forward. You will be refreshed. You will renew your hope.

The Appeals Process

People with disabilities and their families receive services from a wide variety of public and private agencies in Oklahoma. Any agency whether it receives some public funds or even if it operates 100% from private funds will have some kind of appeals process. That appeals process may be an internal process or it may be an external process or it may involve both.

If a consumer receives services from the Department of Rehabilitation Services, that person may take their concern to a supervisor within the agency. The consumer of services from DRS may elect to contact the Client Assistance Program outside the agency to resolve a concern. The consumer may also elect to do both.

The appeals process will probably be written into the policies and procedures of the organization you are dealing with. It is important that you follow the steps of the appeals process if you are going to successfully grieve an issue.

Sometimes there will be time lines on when something has to be done. If you fail to do something within that time line, you may forfeit your right to continue the grievance process.

For instance, to request a Fair Hearing in the Oklahoma Department of Human Services, you have thirty days after receiving a written decision. If you wait thirty-one days, your request for a Fair Hearing may not be honored. Knowing that appeals process can be critical in getting your needs met. Many people have no idea how to appeal a decision.

In this section of this book on advocacy, the focus will be on the appeals process of some of the principal agencies which work with people with disabilities in Oklahoma. Even though all agency appeals will not be discussed, information will be provided to enable you to ask the right questions. There are common things in appeals in every organization.

Appeals will be discussed in general. This book is not meant to be considered the definitive and final information on everything you will need to know for a particular agency's appeals process. Agencies do make changes to their appeals process from time to time—generally not big changes, but changes nevertheless.

For definitive and final information on appeals, always contact representatives of the program within which you are grieving an issue. Ask for written information on their appeals process.

If that written information appears to differ from what you read here, by all means follow the written information you receive from the agency. No one has the power to speak for another agency except the duly-authorized representatives of that agency itself.

It is not the purpose of this book to tell other agencies how to structure their appeals process. It is the purpose of this publication to enlighten the general public that in many cases an appeals process does exist and to provide some general information about appeals in some agencies which serve people with disabilities.

This book will refer you to websites, publications, and job titles of people who can assist you further in learning the details you need to grieve your issue. You may add to this your own research by asking questions and requesting information.

It is also important to say that following the appeals process faithfully and with perseverance does not guarantee that you will receive a favorable decision. It only means that you will receive a proper hearing of your issue.

You will have the opportunity to present your evidence. You will have a forum in which to discuss your concerns. With this understanding, let's proceed ahead and look at how to go about appealing a decision in a way where we may be heard. Let's begin by addressing how to grieve an issue within the Social Security Administration.

> …following the appeals process faithfully and with perseverance does not guarantee that you will receive a favorable decision.

Social Security

The Social Security Administration defines disability as **"the inability to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment(s) which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months."** Notice that this definition is built around the inability to work due to a severe disability. It is not specifically built around having a disability as such.

Many people become frustrated when they are turned down for Social Security disability payments when they have an obvious disability that no one could deny. But, Social Security defines disability as the inability to work in any capacity due to a severe disability. Many times an individual may have a disability, but they are able to work in some capacity even though that job might be different from what they did previously.

Social Security is the <u>only</u> program in the state of Oklahoma which provides cash assistance to people with disabilities. That is said with one slight qualification. If you are a person who has been declared disabled by Social Security, you may be eligible for a very small state check if you also qualify for Medicaid.

Social Security disability payments come in three forms for people who have disabilities. If a person with disabilities has never worked or has worked with insufficient quarters paying into the Social Security system, that person may apply for Supplemental Security Income (SSI). SSI is also for a person with low income and low resources.

If a person has worked and paid into the Social Security system sufficiently according to the rules set up by the organization and that person develops a disability, they may apply for SSDI (Social Security Disability Insurance). SSDI monthly payments are typically larger than SSI payments depending on the length of time a person has been contributing into the system and the amount of their contributions.

If a person receives SSDI assistance and that amount is actually smaller than the minimum SSI payment would be, that person may be eligible for both SSDI and SSI. (Ask your Social Security representative if you think you may be eligible for both programs.)

Occasionally disabled children of a deceased parent who has contributed to the Social Security system may be eligible to draw Social Security benefits based on the work history of that deceased parent. Generally that payment based on a parent's contributions would be larger than what the child would draw from SSI alone.

One of the most common concerns that people with disabilities have when calling the Office of Disability Concerns is a denial from Social Security of their application for benefits. This is quite understandable.

People have often left their employment because of their disability. A person may have no income whatsoever. Expectations are that Social Security will provide the income they need for living expenses. When Social Security denies this person's application for disability payments, the person may quickly be plunged into financial crisis.

It is hard to focus on the step-by-step appeals process in Social Security when a person is faced with an eviction from their home or mounting medical bills connected with their disability. Whatever you can do to ease your financial burden while you are appealing a decision by Social Security will help you focus your energies.

When you make application for Social Security disability payments, Social Security collects your demographic information to assure that you qualify programmatically for their program. They turn over all of your medical information to the Disability Determination Division of the Department of Rehabilitation Services for determination of your disability and how that affects your ability to work.

Social Security contracts with a state agency to process the medical portion of your application according to Social Security rules and regulations. Most people are not aware of this. The Disability Determination Division of the Oklahoma Department of Rehabilitation Services is located in the Oklahoma City metropolitan area. An Examiner is assigned to your case materials, and you may call the person assigned your case anytime during the time they are processing your materials.

If the Disability Determination Division has already issued an opinion on your case, and you have begun an appeal, do not call the Examiner at that point because they have already issued an opinion. Forward your efforts to the appeal.

It takes an average of three months (86 days) for the Disability Determination Division to process the medical portion of a typical Social Security application after they receive your materials from the Social Security Administration. DDD is making efforts to shorten that processing time—particularly for people with obvious, severe disabilities which profoundly affect their ability to work.

Some reasons to call the Disability Examiner processing your case would be if you had new medical or psychological evidence to submit which had not been included in your original application. You may have information about how your disability has affected your day-to-day function which you have not provided previously. Or, you may have evidence of efforts you have made to become employed which have not been successful because of your disability.

You may call the Disability Determination Division at 800-877-9977 or 405-419-2200 in central Oklahoma. Be prepared to identify yourself properly, and ask to speak with the Disability Examiner who is reviewing your case.

Now let’s presume that you have submitted your original application and even perhaps have called the Disability Examiner assigned to review your records and have submitted additional, pertinent information to your case.

One day you receive a letter from the Social Security Administration informing you that you have been denied Social Security benefits because Social Security has determined you are able to work in some capacity even though you may not be able to continue working at your original job. What do you do at this point?

Pay particular attention to why Social Security says they are denying your application for benefits. Many people read the word “deny” and see nothing after that point. It is important that you read why your application was denied. You will build your appeal around strengthening your application on that reason for denial. Let me give you an example.

> Pay particular attention to why Social Security says they are denying your application for benefits. … To go back to Social Security in an appeal without addressing their concerns may be a poor use of time.

Social Security denies an application for benefits based on their determination that the applicant is able to work in some capacity. They are not denying that the applicant has a disability. They are saying that this person has a capacity to work in some capacity even though they are not able to work in their original job. This applicant will build their appeal around their inability to work in any capacity. They are responding to Social Security's specific concern.

To go back to Social Security in an appeal without addressing their concerns may be a poor use of time. To respond to Social Security in appeal fully addressing their reason for denial is time well spent. Let's go back to the original example.

Social Security tells a person that they can work in some capacity. How does this person go about disproving that decision? The applicant's opinion is important, but this is not enough to prove that the decision was wrong. What evidence does the applicant have which would cast light on the subject of their ability to work in any capacity?

Let's say the applicant has a letter from their doctor stating that because of disability, they need to use a bathroom every fifteen minutes. This written evidence from the doctor does affect the applicant's ability to work. The letter signed and dated by a doctor is new evidence the applicant will present in their first appeal to Social Security.

What is some other, possible evidence which would be pertinent to the claim of inability to work? Has the applicant applied to work for several different jobs where they appear to qualify and were never selected? Communicate your efforts to your Examiner and submit that evidence to Social Security. This information will be considered.

Just because you are not selected for one particular job does not necessarily indicate that you do not have the capacity to work in that job, but if you have applied for ten jobs in the last six months and have not been selected for any of them, this at least suggests that some employers may feel that you could not successfully work at the job for which you were applying. Communication with your Examiner regarding your attempts at employment and additional medical evidence can fuel an appeal.

Perhaps you have developed an additional disability since being denied Social Security. Let’s say that in your original application, you were claiming a physical disability. In the six months since you made your first application to Social Security, you have been unable to leave home or to do any typical activities. A professional diagnoses you with clinical depression which is a mental disability.

Any new evidence should be presented with the appeal. Applicants who appeal a Social Security decision must **request an appeal in writing within 60 days (plus 5 days mailing time) from the date of the notice they receive.** Under certain conditions, an extension of this time frame can be granted.

The first appeal which is also known as a **reconsideration** is a complete review of all the original materials you submitted plus any additional evidence. These materials are routed back to the Disability Determination Division to a second disability staff other than the original one who processed your information. The second disability staff and medical consultation team will base their decision of the first appeal on all original evidence plus whatever additional information has been provided.

Three further levels of appeal exist if you continue to disagree with the decision offered. After the reconsideration, you may appeal a second time. This second appeal is commonly called a **hearing.** The hearing is conducted by an Administrative Law Judge. Keep in mind that it can take a year or more for your case to be heard by the Administrative Law Judge because of a backload of cases. The individual and/or their representative may come to the hearing and present their case in person.

A “Notice of Decision” will be issued to the individual and their representative. It generally takes approximately 60 days to process the judge’s decision after that case has been heard. Some people feel the Administrative Law Judge is open to a little broader viewpoint regarding disability than the reconsideration level of appeal.

If the Administrative Law Judge issues an opinion which the applicant still disagrees with, the applicant may continue their appeal to the **Social Security Appeals Council**. The Appeals Council is located in Falls Church, Virginia. It is the final, internal step in the Social Security appeals process. Discussion with an Appeals Council member or their staff concerning your case is not normally permitted.

The average processing time for a request for review is about eight months from the date the request is filed until the Appeals Council releases its final action. In individual cases, however, processing time may vary considerably. Your request for review of the Appeals Council must be in writing.

If the claimant disagrees with the decision from the Appeals Council, they may file a civil suit in Federal District Court. This must be done within 60 days from the date you receive the Appeals Council's notice. (There is a charge for filing a civil action in Federal court.)

Many people ask if they need to obtain a representative or attorney to help with their appeal. That is a decision which the claimant will have to make. It is possible that a person like a case manger who knew you well could represent you in your Social Security appeal, especially in earlier appeals before going before an Administrative Law Judge.

Regardless of whether the individual represents themselves, a case manager represents them or an attorney represents them, it is important to document how the person's disabilities have affected their daily **function**.

Typically doctors and professionals will submit information regarding a medical diagnosis of the person, and this information is needed. However, sometimes no information is provided in the original application nor in any of the appeals on how the disability has affected the everyday life of the individual. Let me give you an example.

One man called the Office of Disability Concerns about his application for Social Security benefits. The individual related that he had "trouble with ambulation". This complaint was vague.

When asked for further explanation, he said, "When I leave my front porch to go out to the car, it takes me fifteen minutes to walk the twenty feet to the car." That was of great benefit. It immediately became very clear as to how this person's disability had affected their daily function.

People do not realize they can supplement their file with information on how their disability has affected their day-to-day function. Are you able to sleep at night? Are you able to communicate effectively with your family? Can you walk, and if you can, how do you walk and how long does it take you to walk a certain distance.

You say you have arthritis. How does that arthritis affect your dressing yourself? Does it take you longer to dress yourself than it would a person who does not have your disability? These are the kinds of things we mean when we suggest you provide information on your function and how your disability has affected your everyday life.

Your doctor knows your diagnosis and is able to provide Social Security with the medical information they need, but in many cases the doctor is not aware of how you function in everyday life activities. You may document this information for yourself, sign it, and date it. Add this to the information you are providing for determination of your claim for benefits.

Even better than this, prepare your functional documentation and ask your doctor to sign it and date it on their letterhead. With the doctor's signature, it becomes medical evidence which is given the highest priority by those reviewing your application.

People often wonder about the decision to employ an attorney. In the early stages of your appeal while your case continues to be reviewed by a Disability Examiner at the Disability Determination Division, an attorney may or may not be of special benefit.

At the hearing level before the Administrative Law Judge, an attorney may be of more benefit. It is your decision to make. Social Security has a publication entitled *Your Right to Representation* (Publication No. 05-10075). Call the national, toll-free Social Security number 800-772-1213, TTY 800-325-0778 to request this publication. The Disability Law Center with offices in Oklahoma City (800-880-7755) and Tulsa (800-226-5883) maintains a list of attorneys who take Social Security cases.

If you desire information on the status of an appeal, contact the toll-free Social Security number at 800-772-1213, TTY 800-325-0778. You may also contact your local Social Security office or your local hearing office.

Some other Social Security publications which may be of benefit to you are *Social Security Disability Benefits* (Publication No. 05-10029) and *Disability Evaluation Under Social Security* (Publication No. 64-039). This publication is intended primarily for physicians and other health professionals. *Answers for Doctors* *and Other Health Professions* (Publication No. 64-042) may also be of benefit in your research.

The Social Security website is www.socialsecurity.gov. If you have web access, it is worth your time to browse this information. You will be able to find the nearest Social Security office to you on this website. We have 21 Social Security offices in Oklahoma. They are located in Ada, Ardmore, Bartlesville, Chickasha, Clinton, Duncan, Durant, Enid, Hugo, Lawton, McAlester, Miami, Moore, Muskogee, Oklahoma City, Ponca City, Poteau, Shawnee, Stillwater, Tulsa and Woodward.

As a post script regarding your eligibility for Social Security disability benefits, the Social Security Administration will conduct periodic reviews of any person who is receiving benefits. It is possible for a person to be approved for benefits and at some later point to have benefits stopped because medical records show significant improvement of their condition. If you disagree with this decision, you may appeal as has already been described.

In your efforts to receive Social Security disability benefits, do not hesitate to use the services of your elected representatives. Since Social Security is a federal program, you may contact either of our two senators representing Oklahoma in Washington, D.C. and/or your Congressional representative.

If you do not know who your federal representatives are, call your local county election board. (The county election board should be listed in the blue pages of your telephone book under county government.)

These governmental representatives will have local addresses in their district as well as Washington, D.C. contact information.

Many federal senators and Congressional representatives will have people on their staff who deal specifically with Social Security constituent concerns.

Special Education

Many parents, friends and family members contact this office regarding a child who is receiving special education through the public school system. During any given school year Oklahoma has about 94,000 children who are receiving special education services and have an individualized education plan (IEP).

When families have children in special education, they should receive a copy of *Parents Rights in Special Education: Notice of Procedural Safeguards* to inform them on their rights and responsibilities from the school offering services. Keep this book in a safe place for further reference, and keep a copy of your child's IEP so that you know exactly what services the school has agreed to provide.

The Individualized Education Plan is an important document because it drives the services your child will receive. If the service is not listed in that plan, it most likely will not be provided. Even if someone has promised you something verbally, it does not become official until it is written into the IEP.

> The Individualized Education Plan is an important document because it drives the services your child will receive.

IEP’s are reviewed annually, but IEP meetings may be held more frequently if a need arises to review the IEP. Behavioral concerns and/or medical concerns are frequent reasons to request a meeting, but anything which affects your child’s performance at school can be a reason for the Team to meet again.

Parents may request that particular school personnel be present at their child’s IEP meeting. They may invite other people who impact their child’s life. Neighbors, Sunday School teachers, pastors, and other family members may provide valuable information to the IEP team to give a more rounded picture of the child’s performance in multiple venues.

Individualized education Teams are <u>not</u> meant to be adversarial where a parent is pitted against a school system. Ideally the IEP Team should function as a team with all parties working together for the benefit of the child. Many times the child also participates in the Team by providing valuable personal information which may help the Team decide what services will meet that child’s needs.

Just because a service costs more does not mean that service is a better one. Sometimes a child’s needs are great enough to merit a special staff person assigned to assist that child during the school day. Sometimes that need can be filled through a peer counselor—that is, another student who does not have disabilities who volunteers to assist the student with disabilities.

As a parent or family member of a child with disabilities in the public schools, you have a key role to play in the IEP team. You know how your child functions in the home environment. Sometimes a child’s behavior may be very different from one environment to the other. This is valuable information.

Parents may become involved in the education of their children by providing a structured time at home for their children to complete assignments from school. Parents may reward their child with something the child likes for good behavior at school and completion of assignments. Children may earn time on the computer or a special television program or time to “hang out with friends” through good school reports and finishing assignments.

Parents have knowledge of everyday functional abilities which will help their children in life after they have graduated from school. Some schools build the child’s curriculum around academic concerns when they should really be concentrating on things which will help the child to function more successfully as an adult. Let me give you an example.

One mother called this office concerned that her child was failing to learn how to read even though this child was already fourteen years old. She explained that efforts had been made for years to accomplish this goal and had never been successful. What could be done?

It may be a part of your child’s disability that learning to read is not a practical goal. Functional skills like learning how to warm food in the microwave may be a practical skill which the child can learn which would be of enormous benefit in the adult world.

To go back to reading and writing, a child may have limited abilities in these academic areas. Time spent learning to fill out a job application may be valuable, practical writing skills for that student. Don’t hesitate to provide information to the IEP Team on needs your child has now which will affect their ability to function as an adult.

You may have some idea how your child's disability affects their ability to function in the school environment. Schools provide therapies such as physical therapy, occupational therapy, and speech therapy based on how those therapies will help your child function at school.

Certainly if your child is experiencing a greater contracture in the hand they use to write, that child will have greater difficulty writing. You may bring this to the attention of the Team and request help in addressing the contracture of the hand.

Teachers and school personnel are the experts on education. It is important that the IEP Team recognize professional expertise and respect it. Parents can be of enormous benefit to teachers who are engaged in preparing children for the challenges of the adult world. Good communication between parents and teachers is of great benefit to the child with disabilities.

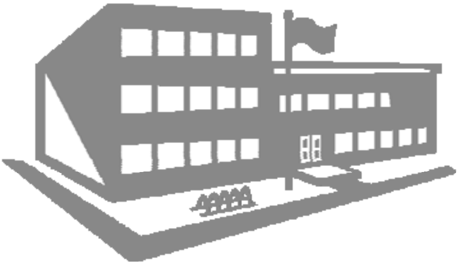
One mother whose son had autism explained how she and her son's teacher sent a notebook back and forth between home and school giving each other important information on her son's performance at home and school.

Good communication does not mean that family and school will agree on every part of the child's education, but it does mean that they will be willing to discuss their different opinions and attempt to reach a solution. Let's look at some ways that families and schools can use to come to an agreement on the education of a child with disabilities.

To resolve an issue in Special Education:

If you have a concern about the special education of your child, there are four avenues which you can use in Oklahoma to resolve your concern. You may contact the school district. You may contact the SEA (State Education Agency). You may seek Mediation through one of the Early Settlement Centers in the state. Finally, you may seek Due Process to formally resolve an issue.

These ways to grieve an issue are not mutually exclusive—that is, just because you do one of them, you are not excluded from using the other methods. Mediation may always be used at any stage of resolving your issue. Due Process is generally the final stage of appeal in resolving your concern.



Your local school district is generally your first avenue when you have an issue with special education in your school. You will have an opportunity to voice your concerns at your child's IEP (Individualized Education Plan). You may contact the principal at the school where your child attends. You may also contact the School Board of the school district in which you reside.

To address the School Board at a regularly-scheduled meeting, you must call in advance and request to get on the agenda of the board meeting. If you are not on the agenda, you will most likely not be allowed to speak.

To address the State Education Agency, you must file a formal, written complaint with the Oklahoma State Department of Education, Special Education Department. They have several Compliance Coordinators who may talk with you about the process. Call 405-521-3351 to speak to one of the Compliance Coordinators. As a rule of thumb, your complaint should not be over a year old.

In your written complaint to the SEA, you should include your child's name, date of birth, and current educational placement. You should also cite how the Local Education Agency has violated one of the requirements of federal law.

The federal law governing the delivery of special education services in the United States is the IDEA (Individuals with Disabilities Education Act) which is reauthorized periodically. The State Department of Education will send you its written decision regarding your complaint within 60 calendar days of the receipt of your complaint in most circumstances.

If you are interested in resolution of your concern through Mediation, contact the Early Settlement Center to ask that a mediation session be arranged. In central Oklahoma, call 405-522-7872 or 877-521-6677 statewide.

Who are mediators? Mediators are community volunteers trained in mediation and basic special education issues. They are certified by the Director of the Administrative Office of the Courts and screened to ensure neutrality.

Mediation is scheduled at a convenient time for all parties. It is fair and impartial. It is voluntary. (Both the school and the advocate must agree to Mediation.) It is confidential. More importantly, a Mediation agreement is legally binding on all parties in its decision.

The fourth method of resolving an issue in Special Education is through filing of Due Process. Due Process is utilized in only a small fraction of cases annually in Oklahoma, and it is utilized usually after other methods of resolution have been attempted.

A Due Process may be filed in writing using either a form or a letter in which you include your child's name, address, school, a description of the facts and your idea of how the issue could be resolved satisfactorily.

Your request will be assigned to a hearing officer. A resolution period of 30 days begins to allow time for the parties to attempt resolution of their issues themselves.

During the resolution period of a Due Process, the parties may come to an agreement. If the parties do come to an agreement, they must put this agreement in writing and sign it. At this point their agreement becomes legally binding, enforceable in state or federal district court.

A Hearing occurs after a resolution period if no agreement is reached. The hearing officer is expected to be fair and impartial. The Hearing will produce a decision within 45 days unless one of the parties has requested an extension.

The Hearing decision is final unless an appeal is requested within 30 days of the decision. If an appeal is requested, an appeal officer will examine the entire Hearing record, seek additional evidence and give the parties the opportunity for oral or written argument.

Any party in the Due Process procedure has the right to bring a civil action if they disagree with the decision of the appeals officer. This action must be brought within 90 days from the date of the decision of the appeals officer. The court will base its decision on the preponderance of the evidence and grant relief it determines appropriate. (Keep in mind that pursuance of your cause in civil court will be at your expense.)

In all these methods of dispute resolution, remember that you must follow accepted procedure. Failure to follow procedure will result in dismissal of the educational concern before it has the chance to be heard.

Schools employ attorneys to represent them at certain points in the dispute resolution process. **The Disability Law Center** in Oklahoma City and Tulsa has attorneys on staff and frequently represents families in their concerns for the special education of their children.

The Disability Law Center in Oklahoma City may be contacted at 405-525-7755 in central Oklahoma or 800-880-7755 statewide. The Disability Law Center in Tulsa may be contacted at 918-743-6220 locally or 800-226-5883 statewide. If the Disability Law Center accepts your case, you will not be charged attorney fees.

If you have a concern about the special education of your child, you may also contact the Special Education Resolution Center in Tulsa. (Due Process complaints are filed with the Special Education Resolution Center.) Their local number is 918-712-9632 or 888-267-0028 statewide.

The website of the Special Education Resolution Center is Http://serc.okstate.edu. The SERC will provide you information on the procedure you must follow to grieve your issue. They will not provide legal advice on your concern.

The Oklahoma Parents Center is a private, non-profit agency with a wealth of information on the law and issues arising in the delivery of special education services. It is a resource for parents and children receiving services. Call toll-free 877-553-4332 to contact a parent advocate. If you have web access, you may browse www.oklahomaparentscenter.org.

Other resources include www.idea.ed.gov. This website is operated by the U.S. Department of Education and discusses the IDEA (law governing special education). The Oklahoma State Department of Education runs another website www.sde.state.ok.us which offers an entire section on Special Education Services.

Section 504 Accommodation Plans

Some people with disabilities may not need special education with its specialized instruction. This may be the case with a public school student who has a physical disability but is perfectly capable of being successful in regular education classes.

Students in this category may benefit from a Section 504 Accommodation Plan. A 504 Accommodation Plan will outline how the school will accommodate the student’s disability. It can vary according to the needs of the student.

A student with diabetes may need time during the school day to take medications. A student with a mobility impairment may need more time to get to designated places. 504 Plans address conditions which limit a major life activity such as walking, talking, hearing and seeing.

If you feel your child needs some kind of an accommodation in the school but your child does not need special education, you may ask to contact the 504 Coordinator for your school district. Your child may need an evaluation to document they have an impairment in one or more major life activities.

A 504 Accommodation Plan can address the special needs a student with disabilities has in regular education classes. If you would like more information on 504 Accommodation Plans, contact the U.S. Department of Education, Office of Civil Rights (OCR).

The OCR serving the Oklahoma region is in Kansas City, Missouri at 816-268-0550. Go to the website of the U.S. Department of Education at www.ED.gov and type 504 Accommodation Plans into the search box at the top of their home page. The Office of Civil Rights is interested that schools follow proper procedure in identifying students with disabilities and developing a 504 Plan to meet their needs.

Oklahoma Department of Rehabilitation Services (DRS)

Vocational Rehabilitation (VR) helps individuals with disabilities to get or keep a job. In Oklahoma, VR services are provided by the Oklahoma Department of Rehabilitation Services (DRS). Individuals with visual disabilities or conditions that can lead to vision loss are served by DRS' Division of Visual Services (DVS). Individuals with other disabilities are served through DRS' Division of Vocational Rehabilitation (DVR).

The Department of Rehabilitation Services (DRS) in Oklahoma may assist people in applying for a specific job. Typically DRS helps people develop skills they will need to find their own job. The Department of Rehabilitation Services supports people to achieve their realistic employment outcome whatever that may be.

If the applicant does not tell the counselor what they will need to achieve this outcome, this applicant may not receive the service. The DRS counselor will know the obvious things needed, but every person has individual needs. People say all the time, "I didn't know I could ask for that." You can ask for whatever you need to achieve your vocational outcome. DRS may or may not be able to pay for it depending on what their policy allows.

Oklahomans are eligible for vocational rehabilitation (VR) services if they have physical or mental disabilities that create obstacles to employment. VR services must be necessary to go to work.

With this preface, let's go into how to get a case opened to provide Department of Rehabilitation Services. First, keep in mind that there are Department of Rehabilitation Service counselors all over

If the applicant does not tell the counselor what they will need to achieve their vocational outcome, this applicant may not receive the service.

the state of Oklahoma. To apply for DRS services, contact the counselor nearest you.

You may call the state office of the Oklahoma Department of Rehabilitation Services (800-487-4042). Follow the recorded prompts and you will get the contact information for the office closest you. When you get this information, call the counselor and ask that an application and a brochure describing the program be sent to your address.

When you complete your application, the DRS counselor has 60 days from the time they receive your application to determine your eligibility. People become impatient within a couple of weeks and begin to think their application did not arrive or that they are being ignored. Be patient and keep in mind that according to DRS policy they have up to 60 days to respond to an application. (Call the Client Assistance Program if your application has not been processed within this time.)

If you are approved for services, you will be assigned a category based on the impact of your disability on employment. If DRS does not have enough funds to serve everybody who is eligible, the agency will serve those with the most significant disabilities first. Others may be placed on a waiting list under what is known as an “Order of Selection”.

If you have been approved for service and have been identified to be in one of the categories which has been closed for service, that does not mean that you will not be served. It only means that there will be a delay.

As mentioned earlier in this book, if you are applying for any program, keep a copy of your application and a phone log of your contacts regarding the program. Keep your approval letter in that same folder. DRS has 90 days after approving you to complete an Individualized Plan of Employment (IPE) with you. The IPE is the next step on your road to employment.

The IPE is a very important document, and many people do not realize this. It identifies the employment outcome toward which the client is working and identifies services in specific terms to achieve this outcome. Become familiar with your IPE, and don't hesitate to ask questions if there are things you do not understand.

Let's look at some things which you can ask for if you need it to achieve your vocational outcome. You may ask to receive:

- Education and training
- Transportation
- Adaptive aids
- Medical services necessary for employment
- Suitable clothing for a job interview
- Uniforms or tools you need to go to work
- Startup funds for self employment upon approval of your business plan

This is not an exhaustive list. As stated earlier in this book, "Ask for what you need." Your needs must be connected to your vocational outcome. If the DRS counselor states that DRS cannot provide a certain service which you need to achieve a vocational outcome, ask the counselor to provide the written policy which confirms this decision.

If the applicant does not tell the counselor what they will need to achieve this outcome, this applicant may not receive the service. The DRS counselor will know the obvious things needed, but every person has individual needs. People say all the time, “I didn’t know I could ask for that.” You can ask for whatever you need to achieve your vocational outcome. DRS may or may not be able to pay for it depending on what their policy allows.

The Client Assistance Program (CAP) is the federally-designated program that provides clients and client applicants with assistance in obtaining services under the Rehabilitation Act of 1973, as amended. In populous states, there may be many people who work in the Client Assistance Program. In Oklahoma we have only one CAP director, and that position is located in the Office of Disability Concerns.

The CAP director will assist you in understanding the DRS system and solving any problems related to your case. The CAP director will not ask the Department of Rehabilitation Services to act outside written policy of the agency. Sometimes, however, that policy is open to interpretation.

Why would a person call CAP? Here are some reasons:

- If you do not understand what you are being told by your counselor
- If there is an undue delay in your services

- If your counselor has not returned your calls within a reasonable time
- If you disagree with your counselor about your IPE
- If you need an interpretation of DRS policy
- If you are being asked to provide information you don't understand

What can your CAP director do on your behalf? This person will research your problem and call your DRS counselor after having received a written release of information from you. (DRS will not even discuss your case with CAP unless you have authorized them to do so in writing.)

If the CAP director feels DRS needs to do something regarding your case, they will make a recommendation to the counselor or counselor's supervisor. CAP can request an **Administrative Review** of your case with the DRS counselor, the program manager, and the field coordinator to resolve a concern.

If you and your CAP director feel your concern has <u>legal</u> merit after trying to resolve the issue without success, CAP can assist you in scheduling a **Fair Hearing.** **(**You can schedule one on your own also.) During a Fair Hearing, CAP and DRS will have legal representatives discussing your case before an independent hearing officer who is not an employee of DRS. At that time you also will have the opportunity to state your case.

The hearing officer is trained in DRS policy and should be impartial in making a decision. If CAP and the client continue in their disagreement with DRS, they can ask for an **Appeal** of the decision of the hearing officer.

In the case of an appeal, a legal brief is written by the lawyers representing DRS and CAP. This legal brief from both sides goes to a person selected by the Governor to review the decision. If resolution of the concern is still not reached at this level, the client can proceed to civil action brought before any state court of proper jurisdiction or U.S. district court.

While CAP can pay for an attorney on your behalf at the Fair Hearing and Appeal level, the client is responsible for expenses of a civil suit. After saying all this, keep in mind that most issues are settled with a simple call from the CAP director to the DRS counselor. A fair hearing is not always necessary.

As another means to resolve a concern with the Department of Rehabilitation Services, CAP can request **Mediation** of an issue on your behalf before a certified, dispute-resolution mediator. Mediation is completely confidential and allows you to make your own decisions in a neutral environment. Mediation allows you to discuss the issues and explore solutions that work for all parties. If you choose to seek another means of resolving your issue, you can do so at any time.

These are the means to grieve an issue with the Department of Rehabilitation Services. But the public should know there are things they can do <u>before</u> a problem develops. The Department of Rehabilitation Services reconsiders their state policy every year, generally in the late winter.

Public meetings convene in various cities across the state. These public meetings offer an opportunity to have input into DRS policy. DRS is required to notify the public about these meetings.

Consumers are invited to provide input either in writing or in person. If you are interested in knowing when and where these meetings will be held, call DRS State Office at 800-845-8476 or 405-951-3400 in Oklahoma City asking specifically about annual public meetings regarding agency policy and DRS's State Plan. Regardless of whether you have a particular concern regarding DRS policy, the public meetings can be informative about what the agency is considering for the future.

If for some reason you cannot attend one of these meetings, you may contact the CAP director requesting they bring up something which you consider important. The CAP director does attend the annual meeting where DRS considers policy changes and can make requests.

How do you contact the CAP director? When you become a client of the Department of Rehabilitation Services, you should be given a CAP brochure explaining the program and telling you how to contact CAP. Call the Office of Disability Concerns at 800-522-8224 or 405-521-3756 asking to speak with the CAP director. Call 405-522-6706 for TDD or Oklahoma Relay if you are deaf. You may email CAP@odc.ok.gov.

Oklahoma Department of Human Services

The Oklahoma Department of Human Services (OKDHS) is the largest state agency in Oklahoma. An office is located in each of the seventy-seven counties of our state. OKDHS offers a number of programs important to the wellbeing of Oklahomans. They administer the food stamps program. They administer the Temporary Assistance for Needy Families (TANF) program. They administer the Child Support Enforcement program to pursue duly-awarded child support payments.

They also administer the Child Welfare program and the Adult Protective Services program to assure that children and adults in Oklahoma live lives free of abuse and neglect. Child Care is an important division which regulates the care of Oklahoma children in licensed daycares. Perhaps most important of all, OKDHS determines eligibility for SoonerCare (Oklahoma Medicaid) which provides health insurance to over half a million Oklahomans, many of whom have disabilities.

One of the most important ways you may grieve an issue within OKDHS is through requesting a **Fair Hearing**. What types of concerns are common as the public seeks services with OKDHS?

One concern which people frequently have is the denial of a service for which they have applied. This denial should come in the form of a letter from the agency explaining why the individual is <u>not</u> eligible for a particular service.

Another letter from the Oklahoma Department of Human Services which may arouse concern is notice that a service currently received is being terminated. People may have come to depend on

One of the most important ways you may grieve an issue within OKDHS is through requesting a **Fair Hearing**.

a service, and they have no resource to replace it. This decision can cause a hardship to the individual or family involved.

A letter of termination of a benefit should tell the client why that benefit is being cancelled based on OKDHS policy. By all means keep that letter. If you do not understand any part of it, call the person who wrote it asking for clarification.

People have concerns when they receive an official letter stating their services will be reduced. Perhaps they will have to begin paying a co-pay for medical services. Perhaps an Aid to the Disabled monthly state check will be less. Perhaps their food stamps are being reduced.

These three types of decision are considered *adverse* decisions because they affect people adversely who are using these services to meet very real needs in their lives. People have concerns about how they may get certain needs met.

Read the letter you received from OKDHS looking for details. Did the OKDHS worker tell you why your services were being denied, terminated, or reduced? Did the OKDHS worker base their decision on a specific agency policy? Do you have any information that is relevant to this adverse decision which OKDHS does not have?

Let's look at an example. Say you were denied SoonerCare because your income was too high. What if you lost your job or your hours were reduced <u>after</u> you had completed your application? This loss of income may affect the decision which was made on your case. Call your OKDHS worker to let them know that a decision was made which does not reflect your current situation.

Was your TANF case closed because of non-compliance in the job search requirements? If you have new information on your efforts in this area, don't hesitate to share this with your worker. It may result in your continued eligibility for the program.

If you challenge a written, adverse decision from the Oklahoma Department of Human Services, you must challenge it at the level of agency policy. It is <u>not</u> sufficient reason to ask for a **Fair Hearing** based on the fact that this decision will work a hardship on you and your family.

You may indeed ask for the Fair Hearing, but your likelihood of getting the decision reversed by the Hearing Officer is not as high based on that reason alone. It is worth your time to seriously consider why a decision is being made and if you have factual information which would support your contention that the decision was wrong.

How does OKDHS policy apply to your case? If you don't know, ask for that information. Asking for more information is a perfectly legitimate thing to do when you are considering how you will respond to an adverse agency decision. In some cases, you may come to understand why the worker has rendered a certain decision.

You may choose to go no further in your complaint. Keep in mind that if a service has been denied today, you may still re-apply in the future. Policy changes, and you may be eligible down the road even though you are not eligible now.

Let's assume you do have information which would suggest that the agency decision was in error. What can you do? You can ask for a Fair Hearing by notifying the OKDHS worker and/or supervisor verbally or in writing that you would like to have a Fair Hearing based on a decision made on your case. If you choose to request a Hearing in writing, ask for the form entitled *Request for a Fair Hearing* or simply identify yourself and briefly state the issue you are appealing.

If you request a Fair Hearing either verbally or in writing **within ten days** of the date of your denial letter or the postmark of that letter, this request will **stop** whatever adverse action the letter describes **until** the issue is heard and judgment is rendered.

For instance, if the letter states that your food stamps will be reduced next month by a certain amount, that action will not occur until the issue has been resolved. This may be of enormous advantage to you if an adverse action will affect you significantly on an immediate basis.

Even if you do not request a Fair Hearing within ten days, you may continue to request a Fair Hearing for 30 days from the date of your letter or the post mark on that letter. If your issue specifically deals with food stamps, you have 90 days to request a Fair Hearing. You must abide within that time frame or your request for Fair Hearing will not be allowed.

As a rule of thumb, your Fair Hearing will be scheduled between three and six weeks of the time of your request. If you have a concern about the time, call your OKDHS worker. The time frame of the Fair Hearing depends on how many other hearings are scheduled. It can vary for various reasons.

The Hearing Officer assigned to your concern is not a lawyer. He or she is an OKDHS employee from outside your local office. Even though your Hearing Officer is not a lawyer, they are quite knowledgeable about OKDHS policy. They are fully capable of determining if your worker has or has not followed agency policy.

Now let’s discuss your preparation for the Fair Hearing. You may want to bring any documentation or evidence that agency policy was not followed in the decision rendered in your case. Evidence will vary depending on what kind of concern you have. You may invite anyone to the Fair Hearing who can shed light on the matter at hand.

A Fair Hearing is not a formal court of law. The Hearing Officer will issue a decision, however, which is binding unless it is appealed. The Hearing Officer knows policy much better than you do and probably knows the right questions to ask to verify if an agency decision was correct or not. Because of this, the Hearing Officer can serve as your real friend and ally.

This leads us to the question of employing an attorney to represent you at the Fair Hearing. An attorney would probably only be useful in the most complicated of cases. However, it is your right to choose to hire an attorney or not.

Where will the Fair Hearing be held? It will take place in a private room at your local agency office. The Hearing Officer will come to you. How long will the Hearing last? That varies. Your hearing may only last 15 minutes in a very simple case. It may last ten hours in a highly-complicated case. How long will it take the

Hearing Officer to render a decision? That also varies, but generally you can expect a written decision on your case in about three weeks.

If you receive a written decision from the Hearing Officer with which you still disagree, you have 30 days once again to appeal this decision to the Director of the Oklahoma Department of Human Services. (The written decision from the Hearing Officer tells you how to contact the Director.)

The Director will review all materials submitted by the original worker and what has been written by the Hearing Officer and will render a decision as to whether your case has been handled properly according to policy. This is the final appeal within OKDHS itself.

You may actually file a civil case with the District Court of the county in which you live, but this appeal will cost you a filing fee, and you will need to be represented by an attorney.

Here are some tips in your dealings with OKDHS. On your original application, make sure the information you give is accurate and up to date. It will make a difference on your application for food stamps exactly how many people reside at your home. Do not falsify or attempt to hide something on your application. Workers have ways of getting information about you from other sources.

Know the facts about your case before your Fair Hearing. If you know the facts, this will give you confidence during the proceedings. When you tell your story to the Hearing Officer, be clear and concise. If you are discussing something about a particular person, identify that person by name rather than referring to this person as him or her, expecting the Hearing Officer to know who you mean.

Tell your story as if you are telling it to someone who knows absolutely nothing about what happened. Don’t presume the Hearing Officer knows everything you know. Identify the specific issue you are concerned about and stick to that issue throughout your presentation. When you bring up information which is not pertinent to your case, it only lessens your effectiveness.

Be present and on time to the proceedings. If for some unforeseen reason you are not able to be present at a scheduled Hearing, call in advance to show respect for the Hearing Officer and OKDHS representatives. Provide as much advance notice as possible. Your cooperation in the proceedings is important.

You have no need to be afraid of the Hearing Officer or any OKDHS staff who may be present. You have no need to be afraid of any part of the Fair Hearing process. OKDHS staff and the appeals process are there to make sure that citizens just like you get any and all services they are entitled to receive.

OKDHS publishes a pamphlet on the Hearing procedure, publication number 05-40. You may request a copy be sent to you by contacting the OKDHS Records Center at 405-962-1721 or toll-free 877-283-4113.

How do you make an appeal within OKDHS other than the Fair Hearing process? The Office of Client Advocacy (OCA) administers a client grievance program for individuals receiving

DDSD services, children currently in OKDHS custody, foster parents and a few other special groups.

The Grievance Program Liaison at OCA may be reached at 405-525-4859 or 800-522-8014 statewide. Explain your concern and where the person you have concerns about is receiving services. The grievance liaison will be able to refer you to the appropriate Local Grievance Coordinator and offer you technical assistance in navigating through the grievance process.

Some common issues grieved this way might be a natural parent who felt they were not getting visitation with their child as ordered by the Court. Another common concern might be a foster parent contracting with OKDHS who claimed not to be receiving their pay as agreed upon.

Typically a person is referred to their Local Grievance Coordinator to begin a process including several steps at the local level and moving up in administrative level until some sort of satisfaction is achieved. The Grievance Program Liaison will be able to walk you through the steps to assure that your concern is given a proper hearing.

The Oklahoma Health Care Authority

The Oklahoma Health Care Authority is the state agency in Oklahoma which determines issues regarding how the SoonerCare (Medicaid) program will be administered. Many people see the Oklahoma Department of Human Services in this role, but actually OKDHS only determines eligibility for SoonerCare. They do not set actual SoonerCare policy on eligibility or covered medications, equipment and medical procedures.

When a person is approved for SoonerCare, that person should receive the *SoonerCare Provider Directory* which is a provider list and the *SoonerCare Member Handbook.* If for some reason you do not receive this information or if you have misplaced it, call the SoonerCare Helpline (800-987-7767 or 800-757-5979 TDD) to request information be sent to your home.

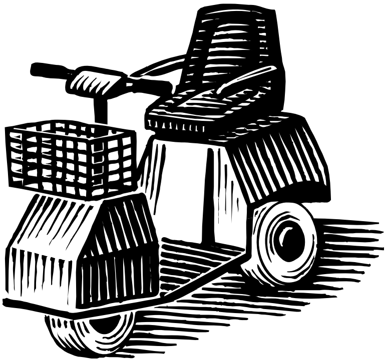
It is important to read the information in the *SoonerCare Member Handbook.* It will provide the member with all kinds of valuable information on how to access health care services. Toll-free numbers are listed in the handbook for SoonerRide (transportation to medical appointments), patient advice, care management, and behavioral health care. If you do not understand something, call the helpline for further explanation.

One of the first things the eligible member for SoonerCare services will want to do is to select a primary-care provider from the provider list in the *SoonerCare Provider Directory.* The new eligible member has from 30-45 days to make this selection and inform the agency by calling the SoonerCare Helpline mentioned above. (The cutoff time to make or change this decision is the 15th of the month to begin the following month.) If the member does not select a primary-care provider, a PCP will be selected for them.

The primary-care provider provides basic health needs. Prescriptions, referrals to specialists, referrals for medical procedures and referrals for medical equipment come through the PCP. Here are some important tips if you are a member of SoonerCare:

- Stay in touch with your primary care provider regularly. Schedule a yearly physical even if you are not sick.
- Keep your social worker at OKDHS updated on any changes such as new income, changed address, or changed marital status.
- Don't hesitate to call the SoonerCare Helpline. They will assist you in resolving your concerns. (The number is 800-987-7767 or 800-757-5979 TDD.)

Some people who are receiving SoonerCare have a need for a mobility device. If this were a need, how would a person address that need using SoonerCare services? It is important for a member to realize that their responsibility in the process is to identify their need and allow their primary-care provider to prescribe what they feel will meet that need.



Let’s presume the primary-care provider has written a prescription for a manual wheelchair. This information would generally be written on a special form outlining a medical necessity.

Usually the primary-care provider will recommend a durable medical equipment (DME) supplier to the member. The member will take the prescription to the DME supplier, and the supplier will fax a form to the Medical Authorization Unit at the Oklahoma Health Care Authority.

The Medical Authorization Unit must prior authorize the form in order for SoonerCare to pay for this equipment. It will generally take two to three weeks for the MAU to make a determination on this request and send a letter to the supplier and to the SoonerCare member regarding their decision. Follow instructions in the letter you receive from OHCA.

The DME supplier will fit you for an approved chair. If someone tries to put you in a chair which is uncomfortable or does not feel right, discuss your concerns with the supplier. When your wheelchair comes, the supplier will notify you.

This same scenario will play out with slightly different highlights for a particular medical procedure or a particular medication you need which requires prior authorization. If you have any questions or concerns in the process of prior authorization, call the SoonerCare Helpline. If the prior authorization is denied, the helpline can tell you why.

If you feel a decision made by OHCA is in error, you may ask to speak with someone at SoonerCare Member Services. You may also appeal any decision SoonerCare has made to deny services or treatment your primary care provider has requested. Call 405-522-7217 or 405-522-7182 TDD requesting an appeal form LD-1.

You may write to SoonerCare, Oklahoma Health Care Authority, attention: Docket Clerk, Legal Division, P.O. Drawer 18497, Oklahoma City, Oklahoma 73154-0497. You must request an appeal within 20 days from when you receive your denial letter.

When OHCA receives the appeal, it will be reviewed and assigned to an OHCA attorney and an Administrative Law Judge within a week as long as all the proper documentation requested is provided.

A Hearing date will be set within 30-45 days of the time the appeals request is assigned. The Hearing will be held at the Oklahoma Health Care Authority. It is an informal process, and the person making the appeal may represent themselves or bring an attorney.

OHCA has three boards. These boards are the Drug Utilization Review Board which makes pharmacy decisions, the Medical Advisory Committee which looks at benefits and policy and the Oklahoma Health Care Authority Board which oversees the agency as a whole.

If you have a concern which you have appealed unsuccessfully in the appeals procedure mentioned above, you may ask to get on the agenda to address one of the boards. The MAC meets in the Oklahoma Health Care Authority board room at 1 p.m. on the third Thursday of the month.

The OHCA Board meets typically at the Oklahoma Health Care Authority board room at 1 p.m. on the second Thursday of the month. The DUR meets from 6 p.m. to 8:30 p.m. on the second Wednesday of every month in the board room at the Health Care Authority.

To get on the agenda of the OHCA Board, call 405-522-7300 which is the main number for the Health Care Authority. Ask to speak to the board secretary and tell this person you want to get on the agenda. The more advance notice you can provide, the better for both you and the board.

To get on the agenda of one of the other boards, call 405-522-7300 and ask to speak to the staff who sets the agenda for that particular board. It is not common for SoonerCare members to address one of the three boards, but it does happen.

If you are a member with a concern about your SoonerCare services, the SoonerCare Helpline is the first place you may call in your attempts to resolve your concerns. If the SoonerCare Helpline cannot address your issue, they will transfer you to SoonerCare Member Services for additional assistance. Member Services may be accessed toll free at 800-522-0310 or 405-522-7171 in the Oklahoma City area.

If you want to learn more about OHCA, you may browse their website at www.okhca.org. Steps you take to advocate for your needs within the Health Care Authority do not guarantee that your concern will be resolved as you desire. The steps you take will, however, provide you a forum in which to present your concerns to people who have authority.

If you are a member with a concern about your SoonerCare services, the SoonerCare Helpline is the first place you may call in your attempts to resolve your concerns.

The number is 800-987-7767 or 800-757-5979 TDD

In Conclusion

I hope these discussions about navigating through some of the programs which provide services for people with disabilities have been of service to you in the process of getting your needs met. The programs cited are only some of the programs which serve people with disabilities.

We have not covered the private, non-profit agencies nor have we discussed people receiving services through nursing homes. Neither have we looked at people receiving services through one of the Medicaid waivers in Oklahoma such as the DDSD waivers or the Advantage Program.

Hopefully we may be able to continue this discussion through other state publications in the future. However, as has been said previously, if you learn the appeals process in one program, you will find many common elements in other programs.

If you have further questions about information provided in this book, call the Office of Disability Concerns at 405-521-3756 or 800-522-8224. We will address your concerns. Advocacy is not always an easy thing. It requires determination and persistence, but it is something which is doable. Agencies are required to have an appeals procedure, and this information is public information.

Some of the things which were mentioned in the first part of this little book are good to re-consider:

- Know Your Needs
- Ask for What You Need

- Know What You Are Feeling
- Focus Your Efforts
- Identify the Facts
- Learn Policy and Procedure
- Contact the Right People
- Develop Support for Your Cause
- Timing and Advocacy
- Persistence
- Know What Motivates the Person or Agency You Are Asking
- Maintain a Record of Your Efforts
- Be Prepared to Compromise
- When Possible, Plan Ahead

Certainly advocacy takes time and effort to be effective, but do not be overwhelmed. Anything you do in any of the arenas mentioned will help. You are important, and it is important that your concerns be adequately addressed. Now that you have read this book, put it down and rest. Give yourself the time you need. You will be refreshed. You will renew your hope.