

Preparing for Their Future: A Teaching for Individuals, Their Parents, and Service Providers

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Preparing for Their Future
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Preparing for Their Future Introduction: There is Hope

A person with a disability needs to learn and understand certain things in order to cope with and thrive with their disability. They also need to educate their parents and service providers.

Parents of kids with a disability need to learn and understand certain things in order to cope with and thrive raising kids with this disability. They need to educate their child with a disability and the professional community.

Caregivers of persons with FASD, autism, turrets, oppositional defiance disorder, OCD, bipolar, sensory integration, ADD/ADHD, RAD, depression, and trauma need to learn and understand certain things in order to cope with and thrive serving individuals with a disability and their parents. They need to educate their clients and their parents and other service providers if they really want to help.

The purpose of this teaching is to assist in doing this. It is written from a different perspective. Its purpose is to truly change everyone's thinking and actions that are involved.

This teaching looks at disabilities from all three perspectives. All three groups really do need to understand disabilities from each of the other two perspectives. Please read this teaching regardless of your experience and understanding of disabilities. As a parent, you need to understand what the person with a disability needs to know. You also need to understand what professionals need to know. As a professional, you need to know what the person with a disability needs to know and what their parents need to know if you are going to help them.

This teaching will talk about:

- The “Brain Shift;” the root cause of the problems persons with a disability face. Also the root cause of so much frustration by everyone involved. This can help us all have unconditional love.
- Outcome based programs – seldom work in the long run.
- Protection – Protection – Protection, the only strategy that truly works.
- “Just the Facts,” this helps parents and professionals stop blaming and shaming each other and the person with a disability. It is meant to encourage people to start seeking answers.
- The importance of **Friends**. We all need them.

- **Calm** should not be an option.
- Why parents and professionals are frustrated with each other, after all, neither is able to fix the problem.
- Why a diagnosis is important and the relationship of your disability with other diagnoses.
- Delayed parenting, not only does it work, it can deescalate the situation, create both calmness and truthfulness and it is convenient.
- Why a developmental growth spurt and brain health are important.
- Forgiveness, we all need to ask for it and receive it.
- Hope and the pathway to it.

Having a disability is nothing new; society has changed. We are no longer a society of physical activity. We have changed to a society of brain activity. Our response needs to change.

If we really want to help, we have to be willing to educate others and ourselves and be willing to change our thinking. We must be willing to look at disabilities from a different perspective. We must be willing to think outside of the box.

This teaching is for persons with a disability, their parents, and all of their caregivers. A few of their caregivers include medical professionals, schools, mental health providers, state service providers, and all too often, the criminal justice system. Then you add to these relatives, friends, clubs, and possibly churches. The list goes on from there.

We all need education, knowledge, patience, and love. May this teaching be a tool to help you achieve this.

This is a three-part teaching, with each part focusing on a specific person or group. However, the information in each part is dependent on the information in the other parts as well. Part one is the foundation which parts two and three expand on. There is a second version of part one, located in the appendix, which may be easier for the person with a disability to read and understand. Pass this teaching on to others. It really can make a difference.

PREPARING FOR THEIR FUTURE

Part 1: What the Person with a Disability Needs to Know

This is part one of a three-part teaching. The focus of this teaching is what the individual with a disability needs to understand. Parents and professionals need to understand these things so they can help the person with a disability understand. The version you are reading is written for the parent and professional. There is a “kid friendly” version of this, which should make it easier for them to understand. It is important that the professionals study all three parts, (personal, parent and professional). Everyone needs to see it from everyone else’s point of view.

Understanding Fetal Alcohol on a Personal Level

As the caregiver of a person with a disability, you need to know everything you can about it and how it impacts you and your family. This lesson is written as if I am sitting with you having a very important conversation. This is an important conversation. You need to read it and then share it with everyone who works with the individual diagnosed with a disability. This would include other caregivers and professionals so that they can begin to understand how the brain affected by a disability functions, or how it doesn’t function at times.

Brain Shift

As a caregiver, it is important that you understand that it is as if the person with a disability will at times have a brain shift. Others with disabilities have described brain shift as: a brain glitch, it affects your good thinking ability, it makes you sometimes forget, you sometimes blow-up, you sometimes get stuck and sometimes shutdown. That does not make your loved one a bad person; it makes them a vulnerable person. It can cause confusion, bad behaviors, and emotional problems. It affects the way they are thought of and the way they are treated. This makes it difficult for them, you, their teachers, and others.

They may appear to be functioning at a higher level and then, when the shift occurs; they function at a lower level. This is hard on them, because they want to always function on a higher level. This is hard on you and other people they come in contact with because you never know when the shift is going to occur. For example, they may want to go someplace where you or other adults who understand them are not going to be. Most of the time they

would do fine, but if the shift occurs, they might get into trouble. You then say no and they become upset, accusing you of not trusting them. They might even say to you, "I've learned my lesson." The truth is they may have learned their lesson, but if the shift occurs, they may blow it. This is not because they want to or because they plan to, but it is part of their disability.

After the brain shift, (and after they have gotten into trouble for a bad choice), more than likely those with disabilities are going to hear things like, "You don't care. If you did care, you wouldn't do stupid things like that. You know better. You only care about yourself. You never think about anyone else." They may even hear people say that people with disabilities have no conscience. That is not true. The truth is, individuals with disabilities sometimes care deeply. They care very much about other people and what they think of them, but when the brain shifts, it impacts everything. This includes the ability to think ahead about other people and how their choice is going to affect them. Rather than having no conscience it is more accurate to say that individuals with disabilities have a "part-time" conscience. This is sad and troubling for them and those around them. However, this is reality. This will affect their life and yours. So, what can they do about this? What can you do about this? What can teachers, employers, and true friends do about this?

This becomes very complicated. First, the individual and everyone involved in their life needs to be aware of this. Denying disabilities exist is not the answer. If you deny there is a problem, then a solution cannot be found. The goal is to help them live a good life.

The second thing you need to do together is find ways to protect them when their brain shifts. Protecting them means keeping them from committing a crime, losing their job, and doing things they would not normally do. Then they will be less apt to either damage relationships or be judged negatively.

Statistics

It is because of the brain shift that persons with some disabilities are often accused of impulsivity, lying, not learning from their mistakes, being a troublemaker, being an emotional wreck, being a bad student, one who makes really poor decisions, or even as a sexual pervert. It is because of this brain shift that they are facing some really hard statistics. For example: 80% of persons with FASD cannot keep a job, 70% will be locked up for mental health reasons, alcohol and drug rehab (they are genetically predisposed), or

most commonly for committing a crime. Other hard statistics that they are facing is the fact that 60% of persons with FASD will have trouble finishing school and over 50% will have sexual involvement that could get them into legal trouble. I do not tell you these devastating statistics to discourage you. You need to realize what they and you are up against, so that you can seek ways around them.

Denying problems will not make them go away. Thinking these things will not happen won't make them go away either. Finding ways to protect the individual may help make them go away. What normally happens is that the individual will deny there is a problem and blame someone else for the problems that do occur. They cannot find a solution to a problem if they do not admit there is a problem. They cannot find a solution to a problem if they are blaming other people for their problems.

It does not seem fair that first, they have a disability and then they have to deal with all this terrible "other stuff". The truth is, it is because of the disability that they have to deal with this "other stuff". Their biggest crime is their vulnerability, because of the brain-shift. It leads to misunderstandings by you, them and those around them. It also allows other people to take advantage of them.

Relationships

They need to learn to be nice and to accept help. Ideally they would even ask for help. If they do these three things, people will be more understanding and will be more able to help. Life will then go better. They must try hard to stay connected to the ones who love them and have been there for them. Ideally, they would build a trusting relationship with you and others who care for and about them. They would then be more apt to listen, even when they do not agree with what they are being told.

One of the hardest and most important decisions they will make is who their friends are. They need to choose friends who are doing well, who have positive goals and are moving towards their goals. Who they choose to be friends with is one decision that is most likely to either cause them problems and get them into legal trouble or help them make good choices that keep them out of trouble. It is also a decision that can help them achieve their goals.

Developmental Growth Spurt

The following list is a list of things that will encourage growth developmentally.

- Eating well - eating whole foods not processed foods, not eating sugar or drinking soda pop (not even sugar free).
- Getting plenty of sleep on a regular schedule. This means that they shouldn't normally stay up past midnight and then sleep past 9 am - unless their job schedule demands it.
- Choosing friends who will encourage them to do well in life.
- Pushing themselves to go beyond doing just enough to get by. If they can't do this on their own, then others and you will need to push them to function at a higher level.
- Do things that will raise their executive functioning skills.
- Check our website www.hayskids.org for specifics about this. By raising their executive functioning skills they will be better able to stay focused, plan, organize, follow-through and cope. This will lead to improved choices and behaviors.
- Working on goal setting and life planning.
- Working on getting organized. This includes using "to do" lists and calendars.
- It is important that they have purpose in life, to serve others.
- They need to be positive. Others will know they are being positive because they are doing positive things.

When they are doing the following things, or choosing friends who are doing these things, they will actually slow down their developmental growth spurt.

- Drinking
- Drugs
- Smoking
- Eating too much junk food
- Staying up too late
- Going to jail
- Sex outside of marriage
- Getting "Hanging Out Syndrome" (See teaching at hayskids.org)
- Playing violent video games or watching violent movies

Achieving Goals

I'm going to give you a list of things that they can do which will raise their chances of being able to accomplish their goals:

- Make a deal with you or someone who really cares about them. If they have trouble with the law, keeping a job, school, relationships, finances, having a place to live, or food to eat, that they will **ask for help**.
- Be aware of how they and their friends dress and look (such as piercings and tattoos) affect other people's opinion of them.
- Learn about any other diagnoses that they have or suspect they have. The most common ones include: Attention Deficit Hyperactivity Disorder (ADHD), Reactive Attachment Disorder (RAD), Oppositional Defiant Disorder (ODD), Obsessive Compulsive Disorder (OCD), Autism, Bi-Polar, Turrets, Depression, and trauma. There may be others also. All too often you can add childhood traumas to the list. If they have sensory integration problems it just makes everything else more intense.
- Some disabilities have no medication that will correct the problem; doctors will attempt to medicate the coexisting conditions. It is important that medications be monitored closely. A medication that is given for one condition can make the symptoms of a second condition worse. If medication is recommended, it is often a long time of trial and error to find the one that gives the most benefit with the least negative affects.
- Recognize their vulnerability.
- Realize adolescence (teen years) can actually go on until they are 25 or so. These years can be very confusing and hard for anyone. Having a disability can make those years even more difficult.
- Do the workbook specifically written for individuals with disabilities. It is called "Preparing for Your Future." You can download it for free at www.hayskids.org. This is a very intense workbook. It will take hours to do. It will make them and you think and talk about things that they or you do not want to think or talk about. It really can help them. Be patient with them. Realize that just because they cannot do something now, it does not mean they will never be able to do it. They must also be patient with others. Everyone is trying their best to help them become the best they can be.
- Transition can be a very difficult period of their life. This is the time that they are trying to move from being a "child" living at home to

being recognized as an “adult”. This is often when life doesn’t seem to be coming together as they think it should. They could have trouble finding a job, finding a place to live, or going to school. This is a good time to ask for help and re-evaluate what is happening.

Hard Subjects

I need to warn you about four very hard subjects:

- The first is jail. Many, way too many, people with disabilities end up getting locked up. This is not because they are bad; it is because they do bad things or make bad choices. I believe this happens because of what I referred to in the beginning as a brain shift.

There are a few things that they must remember if a police officer has to talk to them. First, they must try to stay calm. Then, teach them to ask the officer to call you. Finally they must try to do everything the officer tells them to do.

Remember, if they are sent to jail, it is not the end of the world. It would be best at that point for them to be humble, try hard to obey the rules, and ask for help and accept it. Also, at this point, start working with them on a plan to help them stay out of jail. The most important part of that plan is protection. Protecting them from doing the things that put them in jail and protecting others around them from the poor choices that they make is one of your most important responsibilities. It will probably be necessary for them to change their friends.

Ideally you would have had that plan in place that would protect them and help keep them from going to jail in the first place.

- The second difficult subject has to do with sexuality. It is one of the reasons some people get into legal trouble. This is a real biggie. As one mother said, “I really wish I could have taught my daughter to wait until she was married to have sex.” This subject is so important that when I get a call from parents to talk about their child, I routinely ask about their child’s sexuality. This really is a very, very, important subject.

It is difficult to discuss sexuality because it may be an uncomfortable topic for both you and them. It will be the most uncomfortable the first time. After you begin the discussion, you will find it easier each time. It is vital that they go to an adult that they have built a trusting relationship with to talk about

this very important subject.

- The third difficult subject has to do with whom they pick as friends. I know that I have mentioned this earlier; but it will have a lot to do with the other two subjects I've just mentioned. They must be careful when choosing friends. These friends will probably have a very big impact on all of the choices they make in life.
- The fourth and final difficult subject is school. More than likely it is the one place that they spend a great deal of their time. It is the place that they can like and hate at the same time. This is where they get to be with friends and out from under the direct supervision of their family. It gives them the chance to do what they want and when they want to do it.

However, school also has rules and direct supervision. Unfortunately, most of the people that they will be dealing with are not going to understand them and the brain shift as well as the family does. This means there are going to be more opportunities for them to get into trouble and misunderstandings, especially when there is a brain shift.

Forgiveness

One of the most important skills everyone needs to learn, as we grow-up, is the art of forgiveness. This is especially true if there is a diagnosis.

- They need to forgive the people around them. Everyone makes mistakes, everyday. As we talked earlier, the brain shift makes it very difficult for everyone to predict what is going to happen. That just means that they are human. The individual diagnosed with a disability must remember that you love them and want what is best for them.
- The final person they need to forgive is themselves. They are a person who makes mistakes and bad choices. Bad choices do not make them a bad person. It makes them a person who must constantly work on how to make better choices. They must choose friends who will help keep them on task and out of trouble. They need to do the things that will help them have a developmental growth spurt. They need to ask for help when they see that they are getting into trouble and accept the help from those that love them. Forgiving themselves is a major step toward that developmental growth spurt.

- With all of this forgiving that they need to do, they must not forget that they need to ask for forgiveness. They are going to make bad choices and people are going to get upset with them. When this happens, they must accept responsibility and ask for forgiveness.

I want to conclude this part with a word of hope. Just because someone has a diagnosis of a disability, it does not mean that their life has to be bad. They can live a good life. It may look a little different than what you dreamed it would be, but that is okay. Be patient with them, yourself, and others.

PREPARING FOR THEIR FUTURE

Part 2: What the Parents Need to Know

This is part two of a three-part teaching. The focus of this teaching is what the parent needs to understand. Professionals also need to understand these things so they can help both the person with a disability and their parents. It is important, as the parent that you pass the first part to your kid who is diagnosed with a disability and help them understand what it says. There is a second version of part one which should make it easier for them to understand. This version is located in the appendix at the end of this teaching. You also need to make sure that all of the professionals that work with your child and family are given the entire three-part teaching. As the professional, they need to see it from everyone's point of view.

Crucial Points: you need to know this information not only in your head but it also needs to enter into your heart.

- You need to understand everything in part 1, “What the person with a disability needs to know.” This is important, so read it first. You also need to read part 3, “What the professional needs to know”.
- Being the caregiver for someone with a disability can be extremely intense. Raising kids with disabilities using normal parenting usually does not work well. You need to learn parenting techniques specific to your child's disability.
- Persons with a disability usually do not get worse as they get older. However, they may feel like they are or they may even appear to be. When they are young, they are told what to do, when to do it, where to do it, how to do it, and whom to do it with. That is an incredible amount of structure. But as they get older, the structure naturally becomes less, while at the same time they are dealing with more adult type issues. They may be dealing with choices, such as who their friends should be, sexuality, drinking alcohol, doing street drugs, and relationships. As a person gets further along in school, it becomes more difficult. They might even be dealing with work issues. So at that point, they may actually appear to be getting worse because what is expected is greater and they cannot meet the expectation.
- At times, it is as if their brain shifts. At that moment, it is as if they are a different person. This may appear to happen at random times but will most likely happen when they become nervous, anxious, or upset.

- You, however, may not even realize that they are feeling this way.
- At times, I feel parents want revenge for what their child is doing. I'm not sure it is really revenge. I think it is frustration. I have heard parents say, "I was able to teach my other children." As parents we simply do not know what to do. We try, and try, and try, but we think it simply doesn't work. Nothing seems to. We think that if we give them more consequences, harder consequences, yell louder, get madder, that this will some way get through to them. This tends to only make them more nervous, causing their brain to either shift deeper or make the shift lasts longer.
 - At times they may appear not to have a conscience, at other times they do have a conscience. This is determined by how their brain is functioning at the time. As parents you have to be aware that at anytime their brain may shift into a different mode. I call this a "part-time conscience."
 - A friend of mine once said, "If I had understood the depth of their disability, I would not have taken their attacks so personally." Try to not take their attacks personally; at the same time we need to examine what they say and see if there is any validity in it. We all need to apologize quickly for anything we do or say that is wrong. This includes when we are judging their heart or blaming them. I have said, "What you did was wrong but I should not have blamed you. You will have to have more supervision."
 - Realize that disabilities are often made even more complicated by attachment disorder, childhood traumas, and adoption, foster, or kinship care issues.
 - Understand that often their bad behaviors are because of their disability. They still need to be taught to admit it when they do something wrong. They need to apologize. They need to take responsibility for their own actions and not blame others. This can take years to teach, and they may never learn it completely.
 - Understand that outcome based programs, those programs where your child must consistently achieve at a predetermined level, seldom work in the long run. They may work in the beginning and again periodically but when there is a brain shift, your child will not be able to maintain that level.
 - Realize that, as the parent, you are going to be blamed for things. You are going to be blamed for the difficulties that your child is having, by both the child and the professionals working with them. Understand, the vast majority of professionals have absolutely no idea what it is to

- live with someone with this type of disability
- Do not blame professionals because they can't fix your child, even if they are blaming you. Remember, you are going to them because you couldn't fix your child either. Instead, you need to help educate them so that everyone can stop blaming and then work together to make things better.
 - Realize, all too often, that nothing helps. There is no pill, parenting technique, therapy, or anything short of an act of God that will heal our children's disability. What we must use is protection, understanding, patience and love. A developmental growth spurt helps. Do everything you can to help bring one on.
 - Being calm is extremely important and impossible at times. From a Fetal Alcohol standpoint, if you are not calm it makes them nervous or upset and can cause their brain to shift. From an attachment standpoint, when you are not calm, it feeds the Reactive Attachment Disorder (RAD). That means that when you are upset, in their subconscious, it proves to them that they are right. They can't trust you and that you don't really love them.
 - At times, you have to love them at a distance. As difficult as it may be to understand, love can be overwhelming and cause bad behaviors. There will be times when they simply cannot accept the hugs and comfort that we so often use to soothe someone who is upset. They will need to come to you for those times. You will have to accept that this is the way they are. You can always hope that they may have a developmental growth spurt and change. However, until then, you need to love them, no matter what.
 - Do not blame them or shame them for what they do. That does not mean that you let them get away with bad behaviors. Parents need to look at bad behaviors a different way. We need to look at those behaviors as brain shifts. Someone may argue, "but what if it's just them being bad." The truth is it does not matter. I try very hard not to judge their heart. I try to deal with "Just The Facts." If what they did was because of their disability then they need more protection. If what they did was because they were being bad, they need more protection. Protection usually means more supervision.
 - They sometimes need protection from society and society sometimes needs protection from them.
 - Realize that no matter what you do, many will make very poor choices and will have to be locked up. Parents and caregivers need to understand that regardless of what they do, at times, persons with

disabilities may make ridiculous choices. **Don't take it personally.** This does not mean that you are a "bad" parent or that you have failed.

- You will feel like a failure at times. That does not mean that you are.
- Take care of yourself, and if you are married take care of each other. This is not as a selfish thing, but it is necessary for you to be an effective parent. Raising children with disabilities can destroy you physically, emotionally and mentally because of the stress.

Characteristics

The following is a list of common characteristics that a person with disabilities sometimes have. Realize that they may not have all of these characteristics, or the characteristics may only present when their brain shifts. Just as we are all individuals, persons with disabilities are individuals; some may have more damage than others.

- Impulsiveness
- Short-term memory problems
- Lack of self-control
- Not learning from their mistakes
- Confusion
- Slow processing, which means it sometimes takes them longer to understand what was said and longer to come up with an answer.
- As they are getting older, there often is a lack of incentive, lack of drive.
- Negativity/discouragement
- They often deny that they have a disability.
- They often have even stronger feelings of "I don't need help."
- Drinking/doing drugs
- Choosing unhealthy friends
- Trouble with those in authority/trouble with the law
- Risky behaviors, both sexual and legal
- Academic problems-They may be able read at grade level but not understand what they read. Math is sometimes a problem, as is abstract thinking.
- Running away
- Self-injurious behavior (cutting themselves) or even attempted suicide
- Anger-If they become violent or aggressive when they are angry, this must be dealt with. Do NOT let them hit you or others. Do not allow them to be bullies.
- Stealing-This is a very difficult problem to deal with. Often they do not

- even want or have a need for the things they steal. They simply have difficulty understanding the more abstract ideas of ownership.
- Unstable, emotional and behavioral ups and downs
 - Can't keep a job
 - Ineffective communication. Their behavior is often their way of communicating when they do not have the words or ability to make us understand.
 - Knows right from wrong, but can't do it. They can verbalize what is right and wrong but do not behave that way. Might appear to not have a conscience at times – I call this a part-time conscience. This may be due to a brain shift that has occurred. It means that they have not internalized what they are saying. They have not been able to link those words to an automatic behavior.
 - Totally unreasonable
 - Being at odds with parents and others in authority
 - Multiple diagnoses

They often have very normal desires

- Desire to marry
- Desire to have children
- Desire to provide for their family
- Their biggest desire is to BE NORMAL

Protection

Protection is one of the most important parenting strategies I know. Protecting them from society and protecting society from them. Using home base and/or a levels system can help protect them. (More information can be found on these on the HaysKids website: www.hayskids.org under “Dad’s Seminar-Forms.”) Door alarms can really help; it will allow you to sleep at night and still let you know where they are. It can even help them develop self-control.

Sexual safety is a must. This is an area that gets some persons into serious trouble and often leads them into the legal system. You must work very hard to protect them from themselves and predators. You will also need to protect others from the bad choices that these kids make.

A person once told me “regardless of their horrible childhood, regardless of their diagnosis, at the end of the day you have to protect them from the society and the society from them.”

Adolescence

We often think of adolescence as the teenage years, 13-19. In truth, adolescence is more closely related to brain development rather than chronological age. For any child, it is not uncommon to have this developmental period continue through the age of 25. I read a book by a gentleman named David Walsh, titled, Why Do They Act That Way? He explains how the adolescent brain is not fully developed, and how individuals in adolescence sometimes use a different part of their brain for decision making than they will as an adult. He gives a reason, not an excuse, for their behavior. For this reason, adolescence may seem to last longer for an individual diagnosed with some disabilities, because it actually does.

Adolescence is often a very hard period for them and for you. Mr. Walsh says that structure will help them. He tells parents to stay connected. He uses the saying “don’t give them a divorce.” I know often times, for many parents, and myself we want to just say, “Oh, forget it,” and just leave them alone during this time. This is not the right answer. They need help; they need you to keep communicating, to keep connected. They need structure, and they need to learn about adolescence.

It has also been noted that in a few cases, children who have had severe trauma early in their lives have more extreme behaviors. After awhile, they may be able to adapt and function in the structure provided in your home. However, during adolescence, they may actually revert back to the types of behavior that they were demonstrating prior to your structured environment. The problem is that these kids are now functioning at a higher level, so the behaviors will be more advanced and possibly more dangerous. Recognize these behaviors for what they are and be ready to ask for the help that you will definitely need.

Diagnosis

If you suspect they have a disability and they do not have a diagnosis you need to get one. You will need to find a state organization that focuses on their disability and ask for the diagnostic clinics in your area. I recently heard about a professional child physiologist who told a parent that their child probably had a certain problem, but there was no reason to go to the trouble and expense of getting a diagnosis, because there wasn’t anything they could do about it anyway. That is the wrong message for both the parent and the individual. While you cannot cure their disability, there is a great deal that can be done to improve the life of the individual and their

family, who loves and cares for them.

The ultimate goal of getting a diagnosis is to help the individual with a disability to live a better life by reducing secondary disabilities. This will be done through services, education of the person, their parents, their caregivers, and the community. In order to accomplish this, the first step is a diagnosis. I have had parents asked me, “Why would I want to get a diagnosis? The diagnosis will just label my child.” Individuals with a disability are often labeled. Classmates, teachers and community members will label them. There will even be times that they will be labeled by you. All too often they will be labeled as being lazy, troublemakers, oppositional, sexual perverts, stupid, liars, cheats, thieves, and many other things. So, instead of labels that serve no purpose other than name-calling, let’s give them a label that can help them get services. With proper education, it can help people understand them, especially their parents, caregivers, and most importantly, help them understand themselves.

This does not mean we give them a diagnosis and just let them get away with doing wrong. It does mean that we will have compassion, understanding, and that we will hopefully find ways to reduce additional problems. Protecting them is key.

Parents need to understand about their child with a disability so they can learn special parenting techniques. Parents also need to understand so that they will neither blame and shame their child nor blame themselves. Parents need to understand so that they can advocate, educate, and find services for their child. It is a fact that couples raising children with special needs have a higher divorce rate. By helping them understand their child and their child’s difficulties, perhaps we will help to reduce that rate.

Caregivers need to understand, so that they can effectively help the person with a disability and their family. Caregivers need to understand so that they neither blame the person with a disability nor their parents. Caregivers need to understand so that they can help other caregivers to understand, including the legal system.

There are steps, which can be taken before a diagnosis is made, which will help later in making a diagnosis. You need to connect with a social service agency or an organization that understands your child’s disability to get help through the diagnostic process. I go into more detail about service providers on page fourteen under “Services”.

If a person receives a diagnosis, they need to connect with an advocate. The advocate's job would be to answer questions for the family, teach them about their disability, and help educate the child's many service providers, which would also include the school and the legal system.

Developmental Growth Spurt and Brain Health

Some individuals with disabilities will have developmental growth spurts in their late 20s to mid 30's. This means that they can do things that they were not able to do before. These might include living more independently, keeping a job, having a relationship, staying out of jail, and realizing they need help.

You need to study about developmental growth spurts and brain health. Take serious the task of helping them to raise their executive functioning skills. Read the teachings on our web site about brain development. Pay special attention to "Hanging Out Syndrome" and "Executive Functioning Skills". Keep in mind they often have a problem with lack of drive.

School

School can be a very difficult place for many of our kids. One mother said to me, "I do not know how he can force himself to go to school every day. Because of his lack of short-term memory, he struggles academically. Teachers actually blame him, sometimes even telling him that they know he knows the information. He knew it yesterday. Then there is his problem with organization skills; sometimes I will put his work in his backpack and somehow he will lose it before class. Then, you add kids making fun of him, and he has even been beaten up. "

Later, teen years can be very frustrating for them. The developmental gap is widening. They see other kids their age doing things, which they are not allowed or simply can't do. School becomes even more abstract and much more difficult. They may be able to read on grade level but they can't comprehend it. Then add to this, the teacher's frustration, which is often caused by their brain shifting, bad attitudes and behaviors. Then they start hanging out with kids that have bad attitudes and bad behaviors; they are the only ones who will accept them. This can be an incredibly vulnerable and frustrating time in their life.

There are some strategies a school can do which can help. The school must teach their staff about your child's disability. If the student receives special education services, they have an IEP. The school must use a team approach for the IEP; which includes listening to the parent and communicating with them. (It is not the place of the IEP team to blame the parents.) They are to develop strategies that help that individual student be more successful. Think outside the box. Many times our kids need a classroom aid. That person helps them keep on track, remain focused, make good decisions and protect our kids from being taken advantage of because of their vulnerability. A special emphasis needs to be on transitions since these are often very difficult. Try hard to protect and understand our kids; look at them as having organic brain damage. Remember about the brain shift and have compassion.

For some kids, being home bound or home schooled is a better option. With whatever option is decided on, the school and the parents need to stop blaming each other and work together and keep communicating.

Transitions

Normally, during the last couple of years in high school, they begin what is commonly referred to as the transitional years. This can be a very scary time for both them and you. It is especially important at this time that you teach them about their disability just as you would teach a kid with diabetes about his disease. Just thinking that everything will be okay, will usually lead to failure. I have known of too many kids that have been raised in good solid homes who have ended up in jail. That is not to say that if you do absolutely every thing right they will succeed, but at least you will have laid down a foundation for them to draw upon later.

On our web site there is a free 61-page workbook, called "Preparing for Their Future," written for young adults in their transitions years. This is designed for them to work through with a facilitator. One of the advantages of doing the workbook with them is it can open up communications. It not only teaches them about their disability, it helps them to be aware of how their disability has affected their life. It does life planning, teaches them life skills, and it helps to prepare them for their future. It asks some of the tough questions that will make it easier for you to start the conversations about the very hard subjects. I highly recommend it.

There are subjects that you need to talk about with your kid. You need to

talk about the tough subjects. Then you need to do life planning around those subjects. You will then need to design the life skills teaching around their life plan. Some questions that you need to ask:

- What do they plan to do when they turn 18 or when they are finished with high school?
 - Where do they plan on living?
 - Live on their own
 - Living with assistance, and what the level of assistance will be. The level will depend upon their needs.
 - Living at home
 - Living in an assisted living center
 - For some, you need to prepare them for living in a jail.

There are other issues that must be addressed.

- Medical care
- Driving
- Education
- Relationships
- Their vulnerability
- How they will dress
- Their choice of friends
- Marriage
- Sexuality
- Life skills
- Job
- Alcohol and drug abuse, (this includes both street and prescription drugs).
- Money management
- Recreation: it could be through the YMCA, a youth group, or an adult group. It could be going to church. It could be sports. Talk about different forms of recreation.
- Talk about whether they possibly will need a guardianship or conservatory.
- What if they do not have the life skills to accomplish their goals? Will they accept help or reevaluate their goals?
- Any socially unacceptable behaviors
- Plus all the other subjects that come to mind that you really don't want to talk to them about.

You need to teach them normal daily life skills. Life skills such as: cooking, having good hygiene, money management, communicating, and being nice. Then you add to that list their personal one from life planning, which comes

from dealing with the tough subjects. Remember to give them hope.

Team Approach

Put together a team of people to help them. Train your team about your child's disability. The team could be made up of people from the following areas: education – mental health – social services – medical – advocate – parent – criminal justice – sports coach – youth leader from an organization such as YMCA, 4H, scouts - pastor, or elder from a church – an adult friend – a mature sibling - relative – other service providers.

Services

Remember a team approach is very important. Using appropriate services can help everyone. Most referrals come from either a doctor, the school, or from a parent seeking testing or services. For public service help contact your county human services office, and ask for the in-take worker. The most common public agencies that you will be referred to are Developmental Disabilities, Children's Mental Health, Adult Mental Health, or County Health Department. You may also be fortunate to live in an area where you have access to private agencies that can help. Some individuals with disabilities qualify for Social Security. These agencies will then either help you and/or refer you to other public agencies or to private organizations. You can go to our web site for a list of service providers. You will also want to look for state organizations that are specific to your child's disabilities. Sometimes the person with a disability is eligible for medical assistance or for a waiver regardless of the family's income. A waiver is a funding source that is often used to pay for assisted living, respite, staffing, adaptive changes, and services.

Counseling

When I mention counseling, many parents will often show strong emotions of disgust. Many feel it has simply not worked and often times made things worse. All too often, parents have felt the counselor did not understand the disability and made life harder for their child. If you get the right counselor, they really can help. It is good for a person with a disability to have someone to talk to in addition to his or her parents.

When choosing a counselor, interview them first. Find out if they understand your child's disability or if they are willing to learn about it. You need a counselor who will listen to you and not make decisions based solely on what the individual with a disability says. The counselor will need to be reminded that the counselee may not recognize or want help and is likely to

blame others for their own difficulties.

A counselor can be an important part of the team; they can really help. Try to find a counselor who meets these criteria.

Criminal Justice System

Sometimes, persons with disabilities are going to be involved with the criminal justice system. So, as parents, we may need to educate ourselves on how the legal system works.

Often a family's first encounter with law enforcement is when they call for help. By the time the officer arrives things may be calmed down and the officer sees it as just a normal domestic problem. The officer talks to the kid for a while and leaves at times. Ideally the parents need to meet with law enforcement and teach them about their child's disability before that first call for help. This will mean that you need to call the department and make an appointment with a supervising officer, perhaps the chief or sheriff. This officer will then be able to decide who you will work with to put a plan together. Parents need to have notes written in their kid's file, so if law enforcement is called or if their child is arrested, law enforcement will have the plan you worked out together.

If you have to go to court, it does not work to simply tell the judge that your child has a disability and locking them up will not work and that it may make your child worse. What you need to do is work out a very detailed plan to present to the judge. Depending upon the offense, the plan might include house arrest or living in an assisted living center. It often includes therapy and either education or work goals. It might also include probation.

Parenting Techniques - a few of my favorite ones:

- Being calm – The less said and the calmer it is said usually the more effective it is.
- Re-runs – when they have a bad attitude or do something wrong, role-play the correct way. We often do this when we, as parents, have flared out of frustration.
- Delayed parenting – This is waiting until you have time to sit down and gently have a calm conversation about what happened. This is waiting until it is convenient for you. This is giving them time to process what happened. This is waiting until they have a chance for their brain to shift to a calm position. If you try to talk to them when they are nervous or upset, they will deny, lie, or get angry.

- Level System – I have been taught that this does not work. However, if I remind a kid that their behavior could result with them going down a level, they usually straighten up. (See our web site)
- Sitting on the bucket – This just means having them stay close to you. You can use a chair. We use a 5-gallon bucket with a lid because it is easy to move around.
- Not blaming and shaming them- be aware of their brain shifts.
- Realize they have a disability, remind yourself often.
- Door alarms – can help a kid gain self-control. It can help a parent sleep at night. It is necessary when there is a concern about sexual safety.
- Communications – Try hard to maintain it even when neither one of you want to.
- Team approach –If the team understands this can really help.
- Teaching them to work – they desperately need this skill and mind set. This can even help with behaviors. The added bonus is that you get things you need done. This also allows the kid to earn money rather than having you just give them money when they want or need it. This is one of the life skills that they need to learn – money is tied to work.
- Teaching life skills – this is doing them a favor. Teach them what the daily tasks are and how to do them.
- Teach them about their disability. They will fight this, but it is important.
- Be painfully honest with them about their socially unacceptable behaviors and their disability. As you are teaching them be as gentle and loving as you can. Realize you may have to point these out hundreds of times. Do not let them get away with hurting you or others. It is extremely important that they learn that they cannot get away with hurting people or animals.
- Consistency and structure – really helps them.
- Protection, protection, protection – you cannot always do this but you must try. Try to set up safety nets. At times give them enough freedom to blow it. I'd rather they blow it when I am still very involved in their life so we can hopefully teach them how not to do it again.
- “Just the Facts” – don't judge their heart. Whether it is because of their disability or not, it does not matter. Either way, you need to protect them more. This usually means more supervision.
- Consequences are meant to change their behavior, not to “get” them. Do not expect consequences to work all the time. Consequences usually do work until the brain shifts; at which time they seldom

- work. Sometimes consequences may mean you telling them, “just don’t do it again,” or doing a job they really don’t like (such as doing extra dishes), or coming up with something else. You must continue to try and influence their attitudes and behaviors. You may feel the situation is hopeless but you never know when they will demonstrate that they have learned something.
- Thinking Page-This is a cognitive thinking program which we designed. It requires them to fill out a form that forces them to think about what happened. They must identify the cause, come up with a solution, decide on consequences and apologize. The facilitator, usually the parent, calmly discusses it with them and gives the consequences.
 - “Adults talking” - Talking about the kid in front of the kid as if they are not there. Do not allow them to say anything, unless at the end you ask them to. This allows the kid time to process what is being said without them trying to defend themselves.
 - Moral and educational training daily. The moral training should include life situations while the educational training should include functional life skills.
 - Getting them with other kids in a safe, protected environment
 - Love them – even when you don’t want to and they don’t want to love you.

We need to teach them, train them, try to prevent bad behaviors, bad attitudes, and emotional upheavals. This will take consistency and usually many, many, many repetitions. We have to be aware that, at times, when the brain shifts whatever we have taught may not work. We must try. Do not despair. You are involved in a most difficult parenting task. Hope can be found in a support group. Hope is found when you understand their disabilities. Hope is found when you recognize your own limits, which allows you to ask for and accept help. Hope is found when you can remain calm and not judge your kid’s heart. Hope is found when you teach not only your kids but the professionals as well. Hope is found when you continue to learn all that you can about their disabilities and then advocate for your kid and all kids diagnosed. Finally, you will find hope with your unconditional love.

PREPARING FOR THEIR FUTURE

Part 3: What the Professionals Need to Know

This is part three of a three-part teaching. The focus of this teaching is what the professional needs to understand. In order for the professional to most effectively help the individual with disabilities and their family, you need to understand Part 1 (What the Person Needs to Know) and Part 2 (What the Parents Need to Know). As the professional, you need to see it from everyone's point of view. Pass parts 1-3 on to other professionals working with the family. If you are working with a family that has disabilities, pass Part 1 and 2 to the parents. There is a second version of Part 1, which is easier for the individual with a disability to understand. Make sure that the individual with a disability gets that version.

Crucial Points: You need to know the crucial points from part 1 and part 2 plus:

- You need to understand about their disability so that:
 - You do not judge them.
 - You do not blame their parents for the child's actions.
 - You must be part of the team in order to find the most effective way to help and protect the individual with a disability.
 - You can understand that at times nothing helps.
 - You can understand that outcome based programs seldom work in the long run.
 - You realize that at any moment it is as if they are a different person.
 - Doing the opposite of what they've agreed to.
 - Appearing to not know or having forgotten what they're supposed to do.
 - Acting as if they don't care or don't have a conscience.
 - It is at this point that they are the most vulnerable. This can take the form of emotional, behavioral, and mental problems.
 - confusion and pervasive unreasonableness
 - committing crimes
 - sexuality
 - anger and possibly aggression
 - communication problems
 - lack of drive

- not being able to live independently
- At any given moment their brain can shift back. These shifts will appear to happen at random times but will most likely happen when they become nervous, anxious, or upset. This may be related to an unseen trigger from their past. This can be something as simple as a smell or sound. You, however, may not even realize that they are nervous, anxious, or upset.
- Protection, protection, protection always has to be part of every plan.
- Under crucial points we have to mention the criminal justice system, getting into trouble over sexual issues, having problems at school, can't keep a job, needing assisted-living, choosing the wrong friends, probable alcohol and drug addictions, and their vulnerability. Unfortunately these are all too often a part of our children's lives.
- Try to convince them to accept help.
- See if you can make a deal with them that if they are having these problems that they will ask for help.
- Really listen to the parents, ask them what they think. Try to problem solve with them.
- Really understanding the importance of a diagnosis.
- Learning about their diagnosis so that you understand it, but also so you can help the person, their parents, and other professionals understand it.
- You need to study the list of characteristics as given in part 2. This can help you understand your client. It can also alert you to use a screening tool to determine if you need to pursue a diagnosis if they do not have one.
- It would also be very helpful if you would understand RAD, foster care or adoption issues, childhood traumas, and how these affect your client.
- Be aware of the importance of the executive functioning skills and work to prevent "hanging out syndrome". These are explained in more depth on the website, www.hayskids.org.

Protection - The Single Most Effective Plan

With some disabilities, unfortunately, for the most part services that are outcome based (meaning goal oriented) do not work. Residential sexual treatment centers, alcohol and drug rehab centers, mental health facilities, outpatient programs, counseling, jail, probations, and most anything else that would be considered standard services often do not work. This does not mean they never work; they may even work for a little while. It does mean

that they frequently will not work when the system used does not take into consideration and allow for the brain shifts.

So what does work? Protection, protection, protection. Protection normally means more supervision. Some people refer to this supervision as an external brain. It is someone who, because of their very presence, helps them do the right thing. The external brain can have many jobs: such as keeping them on task, keeping them from stealing, having inappropriate sex, getting angry, and doing anything wrong. It can also help by encouraging them to do things, reminding them to calm down, or that they can do it. Let us look at some models of what that might look like in different scenarios.

At home, for a child diagnosed with a disability, most of the child's life is lived in a central location where they know an adult or an aid is either watching or will be at any given moment. At school it might include an aid, or someone keeping them in sight when they are not in the classroom. At church, sporting events, anytime they are away from the classroom or home there would be someone keeping an eye on them. If they know someone is watching them that can help serve as that external brain keeping them from blowing it.

Extreme Cases: a deeper level of protection is needed.

At home: 100% supervision is necessary when they are not in a room with a door alarm on. This is only for extreme situations. It usually requires paid staff. I have most often seen this used when the legal system was involved. I have suggested to parents to use door alarms for timeouts and to help the parent sleep at night. Ideally the door alarm will only be needed for a period of time.

At school having a full time aid may be necessary but having informed trained staff is a must. We need to judge success differently. For one family that I was working with, their son was able to be mainstreamed his senior year at school. His IEP called for him to be graded only on class participation. He was not graded as to whether he answered the question correctly, but was graded on whether or not he answered the question. This may sound ridiculous and at first it did to me. His parents explained to me that he did go to the learning center for math and reading, but he took the rest of his classes with everyone else. They felt that he had learned as much that year being a member of his class when he could, as he would have had he been in the special-education department full-time.

With that said we must also realize that if our children are being disruptive to the classroom an alternative must be found. At times using a homebound program or home schooling is the only feasible answer. In other situations though that simply will not work and another answer must be sought.

There is an old story out there, which unfortunately is true for way too many parents. A parent reports to the school the behavioral problems their child is having. Sometimes at school this kid is doing okay. A well-meaning teacher or counselor will tell the parents that they think they need to lighten up.

Then when the student becomes destructive or possibly hurts someone, the parent is told they need to have more control over their child. For a student diagnosed with a disability, instead of blaming the parents, we need look at the true cause, which is their disability. That is why a staff that is well trained concerning their disability is a must.

Residential treatment facilities: Sometimes the most effective part of a kid being there is it gives the parents a much-needed break. Seldom does the treatment mode work over a sustained period of time. What sometimes works, while the person is there, is structure, supervision, and rotating staff. I've also known kids with certain diagnoses who were kicked out of residential treatment facilities; the staff simply could not deal with the kid. Because of sexual safety issues single rooms are almost a must, with a staff-guarded hall.

I know a person who worked at a residential facility that became so frustrated. Many young adults with FASD and RAD would do okay while confined in their highly structured facility, with full-time rotating staff, and little supervision. The young adult would be discharged from there and then go out and blow it, either being sent back there or to a juvenile locked up facility (jail). This concerned person went out and started a FASD residential facility. The demand was so high that within a couple of years, he had 10 homes.

If you judge the outcome of his homes on the basis of his clients being healed, his program is failing. If you judge the outcome of his homes on his client's safety, for the most part not getting into legal trouble, staying out of jail, and for the most part not hurting anyone, it is a successful program. His clients are eating, have a bed to sleep in, and are under direct supervision.

Criminal justice system: This is important for those who have a child or client getting into legal troubles. Our support group once met with a judge who worked with juvenile offenders. We explained to him why sending our kids to jail seldom helps; instead it makes them worse. He said, “I understand, but what should I do instead.” Unfortunately, we had no answer. It is true that jail seldom helps; instead it makes things worse. What I have learned since that meeting is if we come up with an alternative plan, judges will often try them, even if the prosecutors, the probation officers, and the caseworkers strongly disagree. You must have a very detailed plan to offer before the judge will consider it.

That plan often includes supervised assisted-living, therapy, education plan, funding source, and a willingness on the part of the client to try. I’ve seen these plans work beautifully and I’ve seen them totally fail. I have also seen them appear to be failing but because of someone’s patience and willingness to keep trying, it has been very successful. Shamefully, I admit at times, I have wanted to give up in certain cases, only to see the person grow developmentally and make it past some very major problems.

At times, I think we need to change our thinking in judging whether a program is successful or not. For one young man, he was able to get out of a sexual residential treatment facility where he was totally failing and move into an assisted living center. There he had a sex therapist, and safely graduated from high school. Afterwards, he ended up blowing it and being sent to jail. However, his program worked for three years. I have to think he is better off and that some foundations have been laid that will help him later in life.

So once again I go back to what does work, protection-protection-protection. We have to find ways to protect them from society and to protect society from them. Unfortunately, at times, jail appears to be the only reasonable option. With that said, I do not like that option and I feel strongly we should look for alternatives.

RAD – attachment disorders.

At times RAD is a simple explanation as to why the kid does better at school or with other people. For this same reason, at times, a kid will behave better in a corporate foster home, with rotating staff, than they will in a loving adopted/foster home. A parenting technique, I sometimes teach, is for the parents not to be too loving all the time. We must have unconditional love

for our kids, however, how we show that love may need to be at a distance. Instead, parents need to be nice and to be there when their child is open to being loved. They must let their kids approach them.

I have known many parents who have been accused of being too negative when talking about or filling out forms about their child. There is even a term for this, “Rater bias.” As one mother told me she was at a meeting when she was accused of this, a short time later her child had a meltdown in front of the caseworker. The caseworker apologized to the mother and told her she had never seen her child act that way before.

I am by no means saying that parents are never wrong and that they never blow it. I will say that we need to truly listen to parents.

We need to try to help them. We need to stop judging them. I must admit that I have been guilty of this also. Where we need to place the blame is on their disability. In the case of FASD, I do not mean to place the blame on their mother who was drinking when she was pregnant. We must forgive and teach forgiveness. Blaming the mother will not help anyone but only make matters worse.

Team Approach: In order to truly be a team, this basic theory is very important.

The purpose of consequences (as we prefer to say supports) and programs are not to get them, it is to change their behavior or protect them. Many times I have said consequences usually don’t work; that is true, but it is also not true. Consequences usually do work until the brain shifts; then they seldom work. We have to think in a different way or we are doomed to failure and so are they.

Parents and professionals need to look at bad behaviors a different way. We need to look at those behaviors as brain shifts. Someone will argue, “but what if it’s just them being bad.” The truth is it does not matter; either way they need more protection, which usually means more supervision. Stop judging their hearts.

We need to teach them, train them, and try to prevent bad behaviors, bad attitudes, and emotional upheavals. This will take consistency and usually many, many, many repetitions. Plus, we have to be aware that when the brain shifts, whatever we have taught may not work. We must try.

At times, I almost feel like parents want revenge for what their child is doing. I'm not sure it is revenge, but that it is really frustration. As parents we simply do not know what to do. We try, and try, and try but we think it simply doesn't work. Nothing seems to work. So we think if we give them more consequences, harder consequences, yell louder, or get madder we will, in some way, get through to them. This tends to only make them more nervous, causing their brain to either shift deeper or make the shift last longer.

We can take this same scenario and apply it to the professional community. We as parents are frustrated with professionals because they are not able to fix our kids. The truth is neither are we. We need to work together.

Team approach is going beyond just getting a group of professionals, sitting down at a table and talking about the client. It includes the parents and possibly an advocate for their disability. When the team is meeting, they need to truly listen to one another, ask the parents what they think, and take what they say into account. Professionals need to use their training and experience to help look for ways to improve the person's life and to find ways to protect them. Do not look at the plan as a way to change their behaviors by giving them consequences, "getting" them. That seldom works. As parents we have learned harder consequences seldom work. The old "scared straight" program seldom works. Don't forget, even if a program is working, it may completely fall apart with a simple brain shift.

Each profession needs a specialist. It would be someone willing to learn more about a specific disability. That person would then be the liaison and resource person for that department. They would also go to a professional in that field, or an advocate to learn more, work out plans, and seek advice.

An example of a working model:

- The individual with a disability has been taught about their disability.
- Their parents and all others in their life understand what the individual with a disability, their parents, and what professionals need to know.
- A team approach is used.
- There is no shaming or blaming.
- Everyone involved must truly understand about the brain shift.
- In each profession there is a specialist. This is someone who has received extra training. Someone that others in that profession can go to for questions and strategies. Someone who goes to others for help

- in figuring out strategies.
- That everyone involved is willing to listen to everyone else and is willing to both ask for and accept help.
 - That everyone understands the seriousness of what the person with a disability is up against. The team will never give up.
 - The team is willing to try non-traditional approaches, with the understanding that if it does not work, they will do something else. The team will not blame each other or the person with a disability, if it does not work. They will understand that it is part of their disability.
 - Members of the team understand that the techniques that are usually the most effective are supervision, structure, teaching them again and again and again, patience, calmness, forgiveness, and love.
 - The number one goal for the team is to protect the person with a disability.
 - Having an advocate be part of the team.
 - Never giving up. Realizing that jail may be a must.

Conclusion: Not False Hope

Hope is:

- Parenting and professional techniques specific to their disability
- Understanding brain shifts
- Long-term consistency and structure
- Realizing at times nothing works
- Trying
- Not shaming and blaming or judging their heart
- Unconditional love
- Forgiveness
- Protection
- Being calm
- Teaching and learning about their disability
- Pushing them to help their brain develop

So take your gifts of patience, calmness, forgiveness, knowledge, and unconditional love and go forth and live a good life together.

PREPARING FOR THEIR FUTURE

Appendix: Understanding Their Disability on a Personal Level

*This version was written to be read to, or by those individuals who have disabilities.

Understanding Their Disability on a Personal Level

As a person with disabilities, you need to know everything you can about your disability and how it impacts you. This lesson is written as if I am sitting with you having a very important conversation. This is an important conversation. You need to read it and then share it with everyone you work with. This would include your parents, caregivers, and professionals so that they can begin to understand how your brain functions, or how it doesn't function at times.

As a person with a disability, it is important that you understand that at times, it is as if your brain shifts. Others with disabilities have described brain shift as: a brain glitch; it affects your good thinking ability; it makes you sometimes forget; you sometimes blow-up; you sometimes get stuck and sometimes shutdown. That does not make you a bad person; it makes you a vulnerable person. It can cause confusion, bad behaviors, and emotional problems. It affects the way you are thought of and the way you are treated. This makes it difficult for you, your parents, your teachers, and others.

You may appear to be functioning at a higher level and then, when the shift occurs; you function at a lower level. This is hard on you, because you want to always function on a higher level. This is hard on your parents and other people you come in contact with because they never know when the shift is going to occur. For example, you want to go someplace where your parents or other adults who understand you are not going to be. Most of the time, you would do fine, but if the shift occurs, you might get into trouble. So, your parents say no. You become upset and accuse them of not trusting you. You might even say to them, "I've learned my lesson." The truth is you may have learned your lesson, but if the shift occurs you may blow it. This is not because you want to or because you plan to, but it is part of your disability.

After the brain shift, (and after you have gotten into trouble for a bad choice), more than likely you are going to have someone say things like, “You don’t care. If you did care, you wouldn’t do stupid things like that. You know better. You only care about yourself. You never think about anyone else.” You may even hear people say that people with a disability have no conscience. That is not true. The truth is, you do care. You care very much about other people and what they think of you, but when your brain shifts, it impacts everything. This includes your ability to think ahead about other people and how your choice is going to affect them. Rather than having no conscience it is more accurate to say that you have a “part-time” conscience. This is sad and troubling for you and those around you. However, this is reality. This will affect your life. So, what can you do about this? What can your parents do about this? What can your teachers, employers, and even your true friends do about this?

This becomes very complicated. First, you and those involved in your life need to be aware of brain shifts. Denying it exists is not the answer. If you deny there is a problem, then a solution cannot be found. The goal is to help you live a good life.

The second thing you and those involved in your life need to do together is find ways to protect you when your brain shifts. Protecting you means keeping you from committing a crime, losing your job, and doing things you would not normally do. Then you will be less apt to either damage relationships or be judged negatively.

It is because of the shift that persons with disabilities are often accused of impulsivity, lying, not learning from their mistakes, being a troublemaker, being an emotional wreck, being a bad student, one who makes really poor decisions, or being a sexual pervert.

Denying the facts will not make them go away. Thinking these things will not happen to you will not make them go away. Finding ways to protect yourself may help make them go away. What normally happens is that you will deny there is a problem and blame someone else for the problems that do occur. You cannot find a solution to a problem if you cannot admit there is a problem. You cannot find a solution to a problem if you are blaming other people for your problems.

Your biggest crime is your vulnerability, because of the brain-shift. It leads to misunderstandings by you and those around you. It also allows other people to take advantage of you.

You need to be nice. You need to accept help. Ideally you would even ask for help. If you do these three things, people will be more understanding and will be more able to help. Your life will then go better. Try hard to stay connected with your family and people who have helped take care of you. Ideally you would build a trusting relationship with your parents and others who care for you and about you. Then you would be more apt to listen to them even when you do not agree with what they're saying.

One of the hardest and most important decisions you will make is who your friends are. Choose friends who are doing well, who have positive goals, and are moving towards them. Who you choose to be friends with is one decision that is most likely to either cause you problems and get you into legal trouble, or help you make good choices that keep you out of trouble. It is also a decision that can help you achieve your goals.

You need to try hard to accomplish your goals and stay out of trouble. For some, this may seem impossible. For some, this will be impossible until they are in their late 20s to middle 30s, then they will have what we refer to as a "developmental growth spurt." This means that they will be able to do things that they have not been able to do in the past, such as: keeping a job, staying out of trouble, being able to admit they have a problem, accepting help, and living more independently.

This does not mean that you cannot accomplish your goals sooner. There are things you can do that may help you to have a developmental growth spurt. These things will help your brain to develop and to be healthier.

- Eating well - eating whole foods not processed foods, don't eat sugar or drink soda pop (not even sugar free).
- Get plenty of sleep on a regular schedule. This means that you shouldn't normally stay up past midnight and then sleep past 9 am - unless your job schedule demands it.
- Choose friends who will encourage you to do well in life.
- Push yourself to go beyond doing just enough to get by. If you can't do this on your own, then ask others to push you to function at a higher level.

- Do things that will raise your executive functioning skills. Check our website www.hayskids.org for specifics about this. By raising your executive functioning skills you will be better able to stay focused, plan things, organize, follow through and cope. This will lead to better choices and better behavior.
- Work on goal setting and life planning.
- Work on getting organized. This includes using “to do” lists and calendars.
- It is important to have purpose in life, to serve others.
- Be positive. Others will know you are being positive because you are doing positive things.

While it is important to do things that will help your brain develop and become healthier, it is just as important that you pay attention to and not do the things that are bad for your brain. When you are doing these things, or choosing friends who are doing these things you will actually slow down your developmental growth spurt.

- Drinking
- Drugs
- Smoking
- Eating too much junk food
- Staying up too late
- Going to jail
- Sex outside of marriage
- Getting “Hanging Out Syndrome” (See teaching at hayskids.org)
- Playing violent video games or watching violent movies

I’m going to give you a list of things that you can do which will raise your chance of being able to accomplish your goals:

- Make a deal with your parents or someone who really cares about you. If you have trouble with the law, keeping a job, school, relationships, finances, having a place to live, or food to eat, you will **ask for help**.
- Be aware that how you and your friends dress and look (such as piercings and tattoos) affect other people’s opinion of you.
- Learn about any other diagnoses that you have or suspect you have. All too often you can add childhood traumas to the list. If you have sensory integration problems it just makes everything else more intense.
- Recognize your vulnerability.

- Realize adolescence (teen years) can actually go on until you're 25 or so. These years can be very confusing and hard for anyone. Having a disability can make those years even more difficult.
- Do the workbook specifically written for individuals with a disability. It is called "Preparing for Their Future." You can download it for free at www.hayskids.org. This is a very intense workbook. It will take hours to do. It will make you think and talk about things that you do not want to think or talk about. It really can help you. Be patient with yourself. Realize that just because you cannot do something now, it does not mean you will never be able to do it. You must also be patient with others. They are trying their best to help you become the best you can be.
- Transition can be a very difficult time of your life. This is the time that you are trying to move from being a "child" living at home to being recognized as an "adult". This is often when life doesn't seem to be coming together as you think it should. You may have problems such as trouble finding a job, finding a place to live, or going to school. This is when it is a good time to ask for help and to re-evaluate what is happening.

I need to **warn you** about four very hard subjects:

- The first is **jail**. Many, way too many, people with disabilities end up getting locked up. This is not because they are bad; it is because they do bad things or make bad choices. I believe this happens because of what I referred to in the beginning as a brain shift.

Often your first encounter with law enforcement is when there is a call for help or you have gotten into trouble. You and your parents need to meet with law enforcement and teach them about your disability, ideally, before that first call for help. Call the department and make an appointment with a supervising officer, perhaps the chief or sheriff. This officer will then be able to decide who you will work with to put a plan together. Notes need to be written in your file, so if law enforcement is called or if you are arrested, law enforcement will have the plan you worked out together. Ideally, you need to have this plan in place to protect you and help keep you from going to jail in the first place.

There are a few things that you must remember if a police officer has to talk to you. First, try to stay calm. Next, ask him to call your parents. Finally, try to do everything he tells you to.

Remember, if you are sent to jail, it is not the end of the world. It would be best at that point to be humble, try hard to obey the rules, and to ask for help and accept it. Also, at this point start working on a plan to help you stay out of jail. The most important part of that plan is protection, protecting you from doing the things that got you put into jail and protecting others around you from the poor choices that you make. It will probably be necessary for you to change your friends.

Ideally you would have that plan in place that would protect you and help keep you from going to jail in the first place.

- The second difficult subject has to do with sexuality. It is one of the reasons some people with disabilities get into legal trouble. This is a real biggie. As one mother said, “I really wish I could have taught my daughter to wait until she was married to have sex.” This subject is so important that when I get a call from parents to talk about their child I routinely ask about their child’s sexuality. This really is a very, very, important subject.

The difficulty discussing sexuality is because it may be an uncomfortable topic for your caregivers and you. It will be the most uncomfortable the first time. After you begin the discussion, you will find it easier each time. It is vital that you go to an adult that you have built a trusting relationship with to talk about this very important subject.

- The third difficult subject has to do with whom you pick as **friends**. I know that I have mentioned this earlier, but it will have a lot to do with the other two subjects just mentioned. Please be careful when choosing friends. They probably will have a very big impact on all of the choices you make in life.

- The fourth and final difficult subject is **school**. More than likely, it is the one place that you spend a great deal of your time. It is the place that you can like and hate at the same time. School is where you get to be with your friends and out from under the direct supervision of your family. It allows you the chance to do what you want to do, when you want to do it.

However, school also has rules and direct supervision. Unfortunately, most of the people that you will be dealing with are not going to understand you and the brain shift as well as your family does. This means there are going to be more opportunities for you to get into trouble and for misunderstandings, especially when there is a brain shift.

One of the most important skills each of us needs to learn as we grow-up is the art of **forgiveness**.

- You need to **forgive the people around you**. Everyone makes mistakes everyday. As we talked earlier, the brain shift makes it very difficult for those around you to predict what is going to happen. Even the people who understand the effects of your disability are going to forget and make mistakes. That just means that they are human. Remember that they love you and want what is best for you. The best that you can give them is your forgiveness.
- The final person you need to forgive is yourself. You are a person who makes mistakes and bad choices. Bad choices do not make you a bad person. They make you a person who must constantly work on how to make better choices.

Choose friends who will help keep you on task and out of trouble. Do the things that will help you have a developmental growth spurt. Ask for help when you see that you are getting into trouble and accept the help that those that love you give. Forgiving yourself is a major step toward that developmental growth spurt.

- With all of this forgiving that you need to do, do not forget you need to **ask for forgiveness**. You are going to make bad choices and people are going to get upset with you. When this happens, accept responsibility and ask for forgiveness.

I want to conclude this part with a word of hope. Just because you have a disability does not mean that your life has to be bad. You can live a good life. It may look a little different than what you dreamed it would be, but that is okay. Be patient with yourself and others.

This is part of a larger teaching that can be found at www.hayskids.org.