There are almost as many definitions of self-determination as there are persons who have written about it. Some writers equate it with the degree of control an individual possesses. Others view it as synonymous with the ability of persons to advocate for themselves. Although each of these approaches has its merits, this writer believes that self-determination is best understood through thinking about it as related to people having the amount of control over their lives that they desire in those areas over which they wish to exercise control.

Self-determination therefore includes having personal control and advocating for oneself, but is more than either of these alone. Persons who are self-determined know what they want, are mindful of opportunities to take personal control, and set goals for themselves accordingly. They are assertive, using the skills they have available to get what they want out of life. As they work toward achieving their goals, self-determined individuals check on their progress so that they can adjust their behavior (or their goals) when necessary. As they chase their personal dreams, they seek out information to help them make informed decisions and take some risks. Some of these payoff and allow them to experience the thrill of personal accomplishments. Others are never achieved. When they are successful, self-determined individuals reward themselves. When not able to get what they want or need, they are able to look back and think about what they might have done differently.

The potential for self-determination exists in all persons regardless of their age, or severity and type of disability. This potential, however, has often not been realized by youth and young adults with deafblindness. Due to a variety of factors, individuals who are deafblind have often found themselves with significantly less control over their lives than they desire. Some barriers to greater self-determination are a result of the hearing and visual limitations the disability entails. A second set of barriers faced by youth and young adults who are deafblind has nothing to do with their disability, but rather stems from the environments in which they live. Some people -- professionals and non-professionals alike -- underestimate the abilities of individuals with deafblindness. As a result, they provide few opportunities for youth and young adults who are deafblind to make decisions for themselves and exercise the degree of control they desire. This makes it quite difficult to acquire and refine the skills, knowledge, and attitudes that support self-determination.

Is Self-Determination Important?

A common goal for most adults who work with or parent youth and young adults is that the young people lead the highest possible quality of life. Quality of life, in turn, is highly dependent upon self-determination. Developing and pursuing personal dreams for the future, and having the ability to make informed decisions and choices, effectively speak out for oneself, and problem-solve all make it more likely that individuals will get what they desire and need in life. Just about everything that has been linked with quality of life is in some way connected to and/or facilitated by a person's self-determination.

"The potential for self-determination exists in all persons regardless of their age, or severity and type of disability."
When one talks with youth and young adults who are deafblind, one of the things that becomes abundantly clear is that, for the most part, these are young people who have an intense desire to participate in and be a part of their communities. It is also obvious that many of them have developed an extreme distaste for being placed in the position of being dependent upon others. Self-determination skills directly enhance the ability of adults to live independently within the community of their choice, develop their own career paths, maintain valued employment, and be part of circles of friendship and support. When youth and young adults with deafblindness are encouraged to take charge of their lives, they are being supported to live as fully included members of society.

Supporting Self-Determination During the Transition Years

Youth with deafblindness come to the transition years with varying degrees of experience in exercising self-determination. Some have had little opportunity to communicate their preferences and make choices up to this point, while others are continuing to build on a foundation of increasing opportunities for decision-making.

Typical child development in the area of self-determination flows from those first signals to caregivers that something needs to be changed (cries, movements, posture, facial expressions), through exploration and manipulation of surroundings as motor skills develop, on to self-feeding and self-dressing, to opportunities to choose activities (e.g., "What would you like to do this afternoon?"). And to the early school years where parents, teachers, and other adults guide children to reflect on their decisions and the consequences (e.g., "You decided to leave your game out rather than picking it up. Now one of the pieces is missing. What could you do differently next time?"). One of the keys to this increasing exercise of personal control is communication.

Among the most basic of prerequisites for self-determination, communication skills allow people to effectively inform others of their needs, desires, and decisions. In the case of children with deafblindness, however, development within this area may be painstakingly slow and all too often the focus appears to be placed solely on the child's skills. Although we still do not fully understand how communication abilities develop, it is clear that exposure to other persons communicating plays a role in the process. When children who are deafblind are not able to observe parents and other family members communicating through the use of some form of sign language, their development in this area as well as their ability to begin taking greater control over their lives is likely to lag. It is also critical that, as a child's ability to sign develops, so does that of family members so that they are able to comprehend requests and respect choices. When this does not occur, children are likely to decrease their efforts to exercise control. In the absence of the ability and opportunity to communicate preferences and choices and be understood, significant others make "educated" guesses. Depending on the degree to which that happens, the deaf-blind child may reach adolescence with very limited skills in exercising self-determination.

The transition years are a period during which professionals and parents can work together to prepare youth and young adults who are deafblind to start making informed decisions about the directions that their lives will take as they approach adulthood. This is possible whether students have well-developed capacities for self-determination or come from situations in which these capabilities have not fully developed.

First and foremost, it makes sense for parents to decide together with their sons or daughters over which areas of life the young person will have control, in which control will be shared by parents and the youth, and when parents will retain control. If an individual has had little opportunity to exercise self-determination, a gradual assumption of personal control is likely to be most successful. Once a joint decision is made regarding which areas of life a young person will control, it is critical that these guidelines are adhered to by all.

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For past editions of our newsletter, visit our website.
http://www.unr.edu/educ/ndsip
Second, professionals and family members should model good decision-making practices for deafblind young people. Through carefully describing the steps that are being taken in order to make decisions, young adults can be encouraged to employ an organized, systematic approach to decision-making in the future. This might include, among other things, writing down the decision to be made, listing possible alternatives, and specifying the costs and resources needed to engage in each option. In the classroom, teachers can regularly make the purposes and reasons for their actions known, and encourage students to cue them when they are not providing sufficient information about what is going on in the classroom. They can help students understand their specific responsibilities and then support them in determining "how" they will accomplish various tasks. In both the school and home, young people can be encouraged to set goals for themselves that are challenging but realistic, and can be met in a relatively short period of time. Reminding developing adolescents to regularly check on the progress they are making toward their goals and providing them, when appropriate, with the necessary assistance to change goals that are too difficult or not difficult enough are other strategies that can be used to encourage development in this area.

In addition to making sure that transition-age young people have the chance to take part in school and family-based decision-making, it is also essential that ongoing opportunities are provided for meaningful goal-setting and decision-making in areas that are of a personal nature. This means that youth and young adults need to be given a degree of control over areas of life that are personally important to them. Those areas of life over which a specific young adult desires control are likely to be unique and somewhat different from those viewed as important by parents, siblings, and even friends. The only way to be successful in this endeavor is to talk to youth and young adults themselves and find out what they personally believe to be important, provide them with frequent opportunities to assume partial and eventually full control over decision-making in those areas, and then honor their decisions.

When opportunities to exercise self-determination are provided, many youth and young adults who are deafblind may be less than fully aware of these opportunities due to their hearing and visual limitations. One of the most important functions that teachers, service providers, parents, and other adults can serve is to ensure that young people take notice of such occasions. An awareness of the opportunity to engage in self-determined behavior, however, is necessary but not sufficient for the exercise of personal control. Youth and young adults must also have sufficient information and knowledge to make informed decisions and choices. Making sure that all of the options available in a given decision-making situation are understood, and explicitly reinforcing the young person's use of the skills and knowledge they have available, increases the likelihood of self-determined decisions and behavior.

These ideas are not meant to imply that adults should not exercise guidance and control over developing young people with deafblindness. Such an approach would do little to encourage true self-determination. Rather, it focuses on adults setting limits and providing opportunities to exercise self-determination within specific areas and under a well-specified set of guidelines. In this manner, the exercise of self-determination in a responsible manner will be encouraged. When working to provide increased opportunities for personal control, a balance needs to be struck between supporting developing youth and young adults to challenge themselves and take risks while minimizing their vulnerability. Only when such opportunities are available are young persons able to learn their strengths and capacities as well as the personal challenges they face.

One valuable way to think about this balance is to view the task as one in which a professional's or parent's goal is to minimize rather than eliminate risk. All persons take risks in their lives on a regular basis. The reason most individuals do this is because they believe the benefits of taking the risk far outweigh the possibility of something negative occurring. Encouraging the self-determination of a young person who is deafblind is no different.

Supporting the self-determination of youth and young adults who are deafblind can be a challenge for professionals and parents. It is not a short process, a "task" of the teens and early 20s, but rather a life-long journey. It is not an easy process and can often be extremely frustrating. At times, it will appear much easier for teachers, parents, and others to make decisions for such young people, to do things for as opposed to with them, and to attempt to eliminate the risks to which they are vulnerable. Most of us, however, have the long-term goal of supporting young people to lead the lives they desire to lead and to become valued members of interdependent inclusive communities. In working to support their self-determination, we are making an important contribution to their progress in this direction.

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#1 The right to quality, community services is guaranteed to every individual with a disability.

Educational programs are guaranteed for students. However, community services are not guaranteed for adults even though adults may be eligible for services. This means there may be long waiting lists. These waiting lists are due to limited funds or state priorities for moving individuals from institutions to community settings.

#2 The transition process means getting a job.

A job is important, but other areas need to be considered during the transition process. Some of the areas may include: living arrangements, relationships and friends, leisure time, homemaking, education, health concerns, transportation, estate planning, guardianship, advocacy, and financial needs.

#3 Identifying transition service needs for good transition planning will guarantee a successful transition from school to adulthood.

Identifying transition service needs is an important part of the process. However, making sure transition goals and objectives are met through the IEP is what really counts. Too often, transition service needs are reviewed at annual IEP meetings only to find that nothing has happened.

#4 Team members work well together during the transition process.

Bringing a group of people together does not mean they will automatically work as a team. For example, team members may not understand each others’ functions, roles, goals or terms. Education team members may not be aware that vocational rehabilitation members and services primarily focus on employment and are time limited services. Vocational rehabilitation team members may not be aware that educators should take an active part in job preparation.

#5 It is easy to make decisions as long as team members keep the person's best interest in mind during the transition process.

Group decision making is not easy because what different team members consider important will depend on personal beliefs, values, and experiences. For example, one team member supports a person's choice to work in the community. Another team member believes that adequate supports are available in a sheltered workshop and not available in the community.

#7 Team members have all the answers to all of the questions that may arise during the transition process.

Meeting a person's needs and preferences means finding people who can help. No one team member can possibly have all the answers to all of the questions. For example, the person's family members are interested in meeting future financial needs through estate planning. Other team members may not have the information, but they can provide resources to the family to get additional information.

#6 Choices about services are limited to what is available in the local community.

Often, a person's choices are forgotten when team members choose from existing services without considering new possibilities. For example, all team members agree the person enjoys physical work outdoors in quiet, non-crowded places. However, the only work option presented at the team meeting is assembly work in a crowded, noisy, sheltered workshop. Team members did not search for other possibilities based on the person's preferences.

#8 The monies to cover costs of services for adults with disabilities are from one government source.

Funds for adult services come from a variety of sources. Creating a total funding package often is complicated because monies are provided by various government agencies including but not limited to Vocational Rehabilitation, Social Security Administration (SSA), Mental Health, Mental Retardation/Developmental Disabilities (MR/DD), and Housing and Urban Development (HUD). Each funding source has different application processes and eligibility criteria.

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In our September 2002 newsletter we began a discussion of our child count over the last 10 years. That edition looked at the ages of our children, the major cause of disability, and the degree of vision and hearing loss. If you did not receive our September 2002 newsletter, it may be retrieved from our website. In this edition we review the disability categories under which our children are reported by the school districts and early intervention agencies, the other impairments our children have, as well as where our children go to school and live.

Disability Category. The primary Part B category used by Nevada school districts for identifying children with vision and hearing impairments has changed very little over the past 10 years. Our children have been consistently identified as being "multiply disabled." In fact, over 80% of our children have cognitive impairments, over 80% have physical impairments and over 60% have complex health care needs in addition to vision and hearing impairments. Very few of our children are simply identified as being "deaf-blind."

Educational Setting. The reporting guidelines we followed from 1991-1997 and those we follow now are significantly different and do not allow a comparison over the life of the project. Currently, the majority of children, ages birth thru 2, receive home-based early intervention services. Children, ages 3-5, involved with the project most typically receive their educational services in an early childhood special education setting. The majority of our children ages 6-21 are receiving educational services in specialized classrooms or public specialized schools.

District/Agency. Because Las Vegas is the population center for the state of Nevada, it is not surprising that the overwhelming majority of our children are consistently from Clark County School District. In addition to those students, many of our children receive services from early intervention agencies in Las Vegas (i.e., First Step and Special Children's Clinic). As one might suspect, Washoe County has also educated a fair number of our children while the remainder of our children are "sprinkled" across the state from Elko to Pahrump and everywhere in between.

Living Setting. Since the inception of the project, the vast majority our children reside with their birth or adoptive parents. The remaining handful of our children live in foster homes, homes of extended family members, or residential facilities.

Why Should Children Be Referred to Our Project? Many of you who are familiar with our project know that our purpose is not simply to identify children with impairments in both vision and hearing. We provide these services to parents and teachers of identified children:

♦ assistance in identification of individuals with dual sensory impairment,
♦ provision of on-site technical assistance (e.g., consultants, inservice workshops, program review) to families as well as educational & early intervention providers,
♦ maintenance of a lending library,
♦ quarterly newsletter,
♦ parent access to a parent-to-parent network,
♦ teacher access to a teacher-to-teacher network,
♦ a yearly parent conference
♦ Dissemination of TA documents.

Technical assistance is provided throughout Nevada in the child’s home, school, or early intervention agency. All technical assistance is provided at no cost to families, school districts, early intervention agencies, and others who provide services to children with dual sensory impairments.

Referrals to the project can be made by parents as well as educational, medical, and social service agencies. If you would like to refer someone to the project, please call (775) 784-6471 in the Reno area, or 877-621-5042 toll-free in Nevada, for a referral packet, or visit our website at www.unr.edu/educ/ndsip to submit a referral online.

CATS website is a decision-making tool. Educational teams can follow the ten phase process to determine where and how children who are deafblind can maneuver more successfully. Each phase consists of clear-cut steps for developing patterns of movement or travel routes around or during activity events. Included in the CATS model are video examples, reading resources, checklists, forms, definitions and, where useful, explanations from the related field of Orientation & Mobility (O&M). Although teams using the CATS model are encouraged to include O&M instructors, this isn't always possible. The purpose of Orientation & Mobility also has a somewhat different focus. While CATS identifies opportunities to move more successfully during activities, O&M teaches specific skills needed in both familiar and unfamiliar environments. And while, CATS seeks to create whatever adaptive supports will increase access to typical settings, O&M focuses on individual independence. O&M training also requires a certified O&M instructor while the CATS model uses a team approach to center on a person's active participation in the mobility components of daily routines.
CMV is a virus that infects most people at some point during life. For most people the virus does not cause any obvious illness; there are not any symptoms. If a person does have symptoms, the symptoms might resemble the flu or infectious mononucleosis (i.e., fever, sore throat, swollen glands, fatigue). Some people might have a more serious illness due to a compromised immune system (e.g., AIDS; chemotherapy).

**How Long Does An Infected Person Carry CMV?**

CMV remains in a person’s body throughout life. When a person is infected for the first time, this is called a primary infection. While there is an active infection in the body, CMV will be shed, or excreted, in body fluids. After the active infection subsides, the virus stays in the body in an inactive, or dormant, state.

CMV can become active again at a later date. This type of infection is a recurrent infection and can occur at any time. With a recurrent infection viral shedding might increase. The virus rapidly dies outside the body.

**How Is CMV Spread?**

The virus is spread in various ways. When a person is infected with CMV anytime after birth, it is an acquired infection. When an unborn baby is infected, it is a congenital infection.

**Acquired CMV Infections**

Acquired infections can be spread in 3 ways:

1. **Person-to-person contact:** CMV can be spread from one person to another, usually by prolonged contact with bodily fluids.
2. **Transplants and transfusions:** CMV is sometimes spread from donors to people who receive organs and bone marrow transplants or who receive blood transfusions.
3. **Mother to newborn baby:** CMV can be transmitted to newborns through the mother’s breast milk or by contact with cervico-vaginal secretions at the time of birth. Most newborns who acquire CMV are not at risk for disabilities.

**Congenital CMV Infections**

**Mother to UNBORN baby:** CMV can be transmitted to an unborn baby of a mother with a primary or a recurrent CMV infection. However, a primary, or first, infection is much more likely than a recurrent infection to result in symptoms within the baby. Congenital CMV occurs when an infected mother passes the CMV virus to the developing fetus through the placenta. About 90% of infants with congenital CMV infections are born without symptoms of the virus; these babies are asymptomatic. The remaining 10% of babies will have varying degrees of abnormalities. Babies with observable signs of congenital CMV are symptomatic.

**Effect on Vision**

Babies with symptomatic congenital CMV can have microcephaly (small head size), small body size, little red or purple spots under the skin (petechiae), enlarged liver (hepatomegaly), enlarged spleen (splenomegaly), yellow color of skin and eyes (jaundice), low blood count (anemia and/or thrombocytopenia), pneumonia, seizures, abnormal muscle tone, calcium deposits in the brain (intracranial calcifications), vision loss, and hearing loss.

Some of these conditions present at birth will resolve; however, some children will have life-long disabilities of varying degrees.

Most babies born with congenital CMV have a “silent” or symptom-free infection. As a result of being asymptomatic, the infection often goes unnoticed. Unfortunately, these babies can still be harmed by CMV. Between 10% and 15% of babies born with asymptomatic congenital CMV will develop varying degrees of hearing loss shortly after birth or during childhood. It is possible that these children will also have vision problems or developmental and learning delays.

**Effect on Hearing**

Babies with symptomatic congenital CMV are more likely to have moderate to severe vision problems as compared to those with asymptomatic congenital CMV. Symptomatic congenital CMV can result in retinitis (inflammation of the retina), optic nerve atrophy (shrinking of the optic nerve), macular scars (scars on the vision-producing areas on the retina in the back of the eye), cortical vision impairment, and strabismus (crossed eyes). Although not as likely, babies with silent infections at birth may also have vision problems. Periodic eye exams by an ophthalmologist are essential to monitor (a) eye conditions present at birth and (b) for later onset of retinitis.

**Treatment**

There is no vaccine to prevent CMV; nor is there any specific treatment for congenital CMV. Specific educational and therapeutic services are determined by the child’s unique needs. Education and therapy might include early intervention, special education, physical therapy, speech therapy, assistive technology, occupational therapy, and services from specialists in the fields of vision and hearing.

**Prevention**

CMV is almost impossible to avoid. However, transmission of the virus is often preventable. Most children with congenital CMV will continue to shed the virus through the toddler and preschool years. Those with acquired infections will also shed the virus. Although it is NOT necessary to test to determine if a child is actively shedding the virus, precautions should be taken. Since CMV can be transmitted through contact with infected body fluids (e.g., urine, saliva), care should be taken when changing diapers or coming in contact with a child’s saliva. Precautionary measures include: (a) avoid kissing young children on the mouth or cheek; (b) do not share drinks, food, eating utensils, or toothbrushes; (c) wear disposable gloves when changing diapers; (d) wash hands with soap and water after diaper changes or contact with a child’s saliva; and (e) thoroughly clean toys that children have put in their mouths.

**Websites**

National Congenital CMV Disease Registry  
www.bcm.tmc.edu/pedi/infect/cmv  
Medline Medical Encyclopedia  
Pediatric Bulletin  
http://home.coqui.net/myrna/cmv.htm  

By: MaryAnn Demchak, Project Director
I enjoy your newsletter, and I know someone who would benefit from receiving future issues. I have entered the address below.

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Return to: Marty Elquist  Department of Curriculum & Instruction/282 University of Nevada, Reno  Reno, NV  89557
New Lending Library Resources

Videos

This 2-hour session discusses the adaptation and adjustment continuum; variables affecting sibling experience and adjustment; self-reports and research; implications for parents and children in families that include children with disabilities; and additional resources available on this topic. The presenter is Cathy Groves, a clinical psychologist with over 30 years of experience as an educator and psychologist specializing in families of children with special needs. (2:00:00) (Guide)


Guides

This guide aims to help parents understand the special education process. The law provides children with disabilities a wide variety of protections. This handbook describes such protections and the right to a free appropriate public education and procedural safeguards that include identification, evaluation and placement. It also shows the need for and the value of parental involvement in the special education process.

Journals

Materials in Spanish
Articulos