PLACEMENT, TREATMENT, TRANSITION AND ETHICAL ISSUES WHEN SERVING CHEMICALLY DEPENDENT DEAF AND HARD-OF-HEARING CLIENTS

by

Debra Guthmann, Ed.D, Program Director Kristen Swan, M.A., Family Counselor Cynthia Gendreau, Senior Counselor Minnesota Chemical Dependency Program for Deaf and Hard-of-Hearing Individuals Deaf and hard-of-hearing adolescent and adult substance abusers suffer a particularly severe lack of appropriate chemical dependency treatment services. A complex interaction among various factors within the deaf community and in the CD treatment delivery system exacerbate the difficulty of providing effective treatment. To date, the treatment literature on the deaf adolescent and young adult population is limited, even scarce, as is the availability of treatment opportunities: Fairview Riverside's Minnesota Chemical Dependency Program for Deaf and Hard-of-hearing is the first and sole inpatient center designed specifically to address the needs of this group.

The majority of Deaf and Hard-of-hearing adolescents and adults use American Sign Language (ASL) as their preferred and most skilled mode of communication. Also, most use standard written English at a lower level of proficiency, often because it is their second language. Moreover, ASL, as a visually and spatially grounded language, does not provide a direct "translation" of English forms and the concepts represented by English vocabulary and syntax. Thus, knowledge about CD is not communicated very well in the deaf community--some key concepts and terms in CD treatment simply do not exist in the deaf culture. Beyond that, in treatment settings designed for the mainstream, the language of communication is itself a barrier to participation among hearing impaired adolescents, in both the educational therapeutic and peer interaction dimensions of any well-designed program. In short, treatment is based on a level of English and "talking" that is simply not possible for many hearing impaired adolescents. The severe cognitive and affective shortcomings of treatment programs extending to deaf persons when the language of treatment is English and the language of meaningful use is ASL.

Deaf culture has always had a highly active "grapevine." This contact with each other on crucial news has helped to offset the lag in information flow. Most CD treatment and A.A. meetings

must reinforce repeatedly such basic concepts as group function and confidentiality with greater frequency than would be the case in a mainstream group. The accumulation of such differences makes effective treatment of the hearing impaired adolescent uniquely problematic, especially when the mainstream treatment program is not built on the same cultural bedrock as are the lives of those hearing impaired individuals in treatment.

Fairview Riverside serves chemically dependent hearing impaired adolescents and adults, primarily 16 years of age and up, but as young as 12, with waivers and exceptions based on need. The target population is that group of deaf and hard-of-hearing individuals - nationally and internationally - who:

*are 16 years of age and up with a pattern of pathological use of chemicals;

*have a primary diagnosis of chemical dependency; (individuals with an additional secondary diagnosis of mental illness will be considered on a case by case basis.)

The Minnesota Chemical Dependency Program for Deaf and Hard-of-hearing is part of Fairview Riverside located in Minneapolis, Minnesota. The Deaf and Hard-of-hearing program is part of an acute care facility that is licensed for 110 beds and has been serving chemically dependent adolescents for the past 15 years. Hearing adolescents come from all over the united States and Canada to receive treatment at Fairview Riverside which is the largest inpatient chemical dependency program in the country. Because of its reputation, Fairview Riverside receives referrals for the treatment of Deaf and Hard-of-hearing individuals. It's experience had often been frustrating because most of the staff were unfamiliar with psychosocial aspects of deafness and hearing impaired clients often felt isolated due to their inability to communicate directly with staff and peers. They also found that the assignments used in treatment were not at an appropriate reading level for many of the clients being served.

A proposal was presented to the Fairview Riverside Board of Directors in 1988 to start a C.D. program specifically for deaf and hard-of-hearing adolescents and adults. The Minnesota Chemical Dependency Program for Deaf and Hard-of-hearing individuals was opened in March of 1989. The goals are:

*to take into consideration cultural aspects of deafness;

*communication modalities;

*to be fully accessible;

*to eliminate feelings of isolation;

*recovering deaf role models on staff;

*individualized treatment planning;

*to provide materials in A.S.L. on videotape and modified written English.

The program differs in that all staff are fluent in ASL and knowledgeable about the field of deafness as well as being respectful of deaf culture. All professional services that are utilized at any treatment program, such as Occupational Therapy and Recreational Therapy are part of this program. In addition, a certified teacher of the hearing impaired and a Communication Specialist are on staff.

When setting up a new program it is hard to predict and prepare for the complexity of issues within the population one is intending to serve. Variance and diversity is inherent in any group of deaf people, and is usually more profound than in a similar sized group of hearing people. On the adolescent hearing units at Fairview Riverside's Chemical Dependency programs, they continually have a large enough census to separate patients into units for severely behaviorally disturbed, learning disabled, dual diagnosis- even according to whether they are "victims", "perpetrators" or

"treatment repeaters." On the hearing impaired unit, however, that is not always an option. The groups are often very diversified with both adolescents and young adults, very bright and more intellectually limited individuals, rubella victims, dual diagnosis, hard-of-hearing, as well as culturally Deaf persons and the variance in sign language abilities which accompany them.

In all the treatment groups, hearing and deaf, the patients come from all over the country and Canada. There are both males and females who come with a variety of grief and sexual abuse issues, a wide variety of communication levels, and a mixture of ethnic and racial backgrounds. Some of these special needs are met through men's and women's groups, and culture specific groups (e.g. Native American/Canadian). Since the census does not often allow us to split into groups such as these, we take the opportunity to do some mainstreaming with the hearing groups. This provides some exceptional opportunities for transitioning and realizing commonalities with hearing people. This is also one way we try to help expand our patients' social support system. It is important that for the bulk of their treatment they have the opportunity to be in the "culturally specific" treatment group with other deaf individuals, but there are times when integration has been therapeutic. One patient was given the opportunity to be mainstreamed into a hearing treatment squad. Because he had been on the deaf unit for several weeks prior to his involvement and had gained a basic knowledge of how treatment works, he was able to feel at the same level as his hearing peers and could practice honing the practical skills he had learned. He remarked when he left this group that they had really helped him feel more accepting of his deafness and that he could now be comfortable being "straight" with hearing people instead of only "high." This was an important experience in this young man's transition back to the "real world" where he would encounter more recovering hearing people than deaf people.

Just as there are groups that focus on C.D., grief issues, and men and women's issues, there is one that focuses on Deaf Culture. Issues related to deafness come up during groups which tended to take the focus off of the C.D. issues. Deafness should not be used as the reason a person began using. The treatment must be culturally and physically accessible.

During the evaluation phase of treatment we find the most resistance. Patients are starting to have second thoughts about being in the program and are overwhelmed by the new concepts, rules and structure. During this phase, the concept of "cons and defenses" are introduced. It seems a new experience for these Deaf patients to analyze their behaviors as well as when and why they behave in the ways they do. Working on cons and defenses has met a lot of resistance because it is all relatively new vocabulary, and because the patients tend to translate confrontations from staff related to their defenses as assaults on their already fragile self-esteem. Through lectures, role plays, continual modeling feedback and repetition in therapy group, they begin to see the behaviors and how they impact their progress in treatment. For example, if a person has a particularly difficult time letting go of his/her "macho" image, they may be given "teddy bear" to take care of for a week or so, which represents the feelings and more vulnerable side of themselves. Along with the bear contract, they will usually be given an affirmation or assignment to do relating to macho/vulnerability issues. For the person who likes to "play ignorant," they may be given an affirmation to say before every group such as, "I sometimes play dumb to avoid talking about my problems or feelings, please confront me when I do this." For the person who is trying to "run his/her own show" and refuses to ask for help, they may be put on a contract where they have to ask one of the other patients for help in everything they do during the day. This way, they see how these defenses/cons keep them from realizing the things that are necessary for them to stay sober (honesty, vulnerability, interdependence,

support, etc.) and help them uncover other valuable facets of their personality.

A lot of therapy time is spent on educating and talking about feelings. During Occupational Therapy they have an opportunity to draw a "feelings collage" depicting the major feelings they have felt in their life. It is difficult for our Deaf patients to identify their feelings because they often have not learned feelings vocabulary. We try to help them identify the physiological reactions they have to different feelings. One very bright patient had a very hard time saying what he felt or even knowing what he felt. He continually looked at the feelings chart on the wall and would "try out" a few feelings to see if staff and peers would agree with him. He eventually was able to identify the "hot" feelings he had in his chest that would rise up when he felt angry. Most of the time when patients do a written assignment such as "bad things that happened because of my use," they required to add a feeling word about that behavior. Sometimes they are put on a feelings contract where they have to stand up in group and say "Today I felt ______ because of _____." Of course the biggest problem we run into is the patients being very vague in their description: ("I feel bothered/bad/upset/okay") and they have to be encouraged to be more specific (impatient/sad/angry/content).

Much of the chemical dependency therapy relates to self-esteem issues, and the connection is always made. Assignments are given to help patients express how they feel about themselves when they are using and when they aren't. We try to spend an equal amount of time emphasizing their resources, skills and positive attributes after they have their past negative behaviors in the first step. We will have them make lists of things they like about themselves, or have them interview other people and ask for positive feedback. In nearly all of our patients, the issue of their feelings about their deafness surfaces. Most have not resolved this issue and their lack of acceptance has exacerbated their chemical use. A lot of education is done by our deaf staff relative to Deaf Culture and deafness issues/awareness activities. In the case of the deaf patient who was mainstreamed with the hearing patients mentioned above, he also made the comment that being involved in the treatment program with the varied experiences had helped him finally accept his deafness while also helping his self-esteem.

Our approaches are very direct and confrontive. A lot of reality checks and "if-then" work is done. There is continual emphasis on consequences, both in the here and now (treatment) and from their past. We always relate things back to their behaviors and the choices they have made. No blaming is allowed. We work with them to understand how past experiences within their family or their school situation have affected them. Once they have an understanding and a "window" to their past, it is put back on them: "Now you know and see what happened - what are YOU going to do about it?" Our approach is quite behavioral with the patients being held accountable for their actions and for the choices they make. We have a level system where they earn certain privileges based on meeting certain objectives. When they don't follow the objectives, they may lose certain privileges within that level, or else be dropped a level.

Many of our patients have had conduct disorders and impulsive/aggressive problems. We have utilized a "time out" chair or area when their behaviors are disruptive or inappropriate. Sometimes seclusion is necessary when the behaviors become threatening. Before a patient can "process out" of a time-out or seclusion placement, they need to be able to identify the behaviors that got them there. Then they must talk about what they need to change and how they plan to go about it. This has been difficult for many of our patients since their tendency is to say what they know we want to hear, and then blame staff or patients for what happened. They are continually bombarded

with the issue of "choice" and the behavioral options that they have.

In the actual "step work" which is the heart of the treatment phase we have found that the steps which deal with more concrete issues (i.e. unmanagability of Step 1 and personal inventory of Step 4) are somewhat easier than the abstractness of Steps 2 and 3 which deal with "higher power." The issue of "powerlessness" in Step 1, however, has been a difficult concept for many patients. Since using drugs gives one a "pseudo" sense of power, and since deaf people have historically struggled to feel they have some power or control in their lives, giving up drugs may be even more threatening to their self-esteem. Drugs are also the great equalizer for Deaf and hearing people. A Deaf drug abuser may for once feel part of the group--and perhaps a very valuable, powerful member of a group if he's got some real good "stuff." So keeping the balance between helping them recognize and accept powerlessness, and "empowering" them to make changes and healthy choices is often difficult.

To teach the steps, we use "homemade" video tapes our staff have developed. We have 2nd and 3rd Step and 4th and 5th Step preparatory lectures done by our signing chaplain. We utilize several different contracts or activities to teach concepts of powerlessness and unmanagability. For example, we will blindfold someone for a designated period of time, requiring them to trust and depend on other people for direction and help. For one patient who was struggling with the concept of giving up his control to a higher power and surrendering all his "baggage" and secrets, he was given the contract of carrying around a sheet full of large phone books. Whenever he would reach out and ask for help or share a secret or a problem he was having, a phone book would be removed. He was able to physically feel the difference between "hanging on" to problems and issues and surrendering them. Another patient was struggling with whether or not he wanted to give up drugs. Since his choices were limited and he would most likely have to live on the streets if he chose drugs, he was put on a street person contract where he had to carry everything with him - his clothes, his pillow, his books - as he moved around throughout treatment.

Unit meetings, called "community groups," are a time for patients to confront one another on their attitudes and/or behaviors. They are required to confront their peers on a specific behavior they have displayed, say how they feel about it and give them suggestions about how they can change. This is a difficult process for most, but they do learn some good assertiveness skills and begin to understand how their behaviors do indeed effect other people. These meetings are also a time to give "positives" and "concerns" to their peers. During therapy groups, feedback is a critical component. This is a time where they must "self-relate" and give other observations of the cons and defenses that were evident in their peer's presentation. It spreads the responsibility of "therapy" and helping to everyone in the group - not just the counselors and further empowers the patients to help themselves. They begin to learn the important concept of "mutuality" and are able to begin connecting in a much more intimate and deeper level with their peers and thus develop trust.

As a result of the diversity of individuals and their presenting problems, the program staff has had to be both flexible and creative in their therapy approaches. For example, a young native hearing impaired man from Canada came to us with a long history of serious chemical abuse and no formal or intelligible language system. Much of our approach with this young man was in a visual, dramatic mode. He drew many pictures of his life and experiences which provided an avenue to get information about his use while teaching signs, words, concepts and options for new behaviors. Fairly early in his treatment it became apparent that he had significant residual hearing which we utilized as much as possible through voice interpreters during group and voicing during 1:1 sessions.

At first, staff worked with him on a 1:1 basis teaching through props and pictures. Then they transitioned him into the group therapy sessions. When his attention span wavered due to not fully understanding the signing, he was taken out and given more one to one time. He eventually was able to sit through two groups a day and participate adequately. It was clear that the peer involvement did much for developing his sign skills as well as his self-esteem and understanding of chemical problems. On one occasion he was able to communicate to a peer who was leaving that he felt sad, that he would miss him and that the peer was his friend. He was able to grasp the important concept, in his words/signs, "drink me - cause trouble/messed up!" By the time he left he was using more of his speech and new signs, had developed a positive rapport with the staff and patients, and had an understanding of what other options he had in his life for sobriety. Fortunately some foster care was found for him outside of his reserve where he could life with a recovering native family and continue to be in an educational and vocational program. At last report, he has remained sober. This was an important lesson for the staff. It reminded us to follow the AA principle "keep it simple," and not assume that because he could not participate as fully in the "regular" programming, it didn't mean he could not receive some benefits.

Family involvement is another very important part of any successful treatment program. This has been difficult with our population. Since we are a program that is set up to serve hearing impaired adolescents and young adults from all over the USA and Canada, our families are quite spread out. Getting them to come here for a full week of family programming is extremely difficult. About 25% of the families of our patients have been involved in treatment. There are many issues which are unique to the families of our deaf patients. There may be extra "baggage" due to unresolved issues surrounding the deafness - lack of acceptance, guilt or doubts about decisions that

were made, isolation from their child's "world." Communication is most likely impaired and inadequate for the development of true family intimacy. Some parents have reached such a "burnout" stage with the Deaf person "after all they've done for them through all these years," that they don't want much involvement. Some parents hang on even tighter to their Deaf chemically abusing child or young adult, mostly because of their own guilt as well as their realistic and sometimes unrealistic fears about their child's options for their future. When it has been possible and our census has allowed it, we have had a separate therapy group for the parents of the deaf patients. This helps to normalize the issue of the deafness and not make it the major focus. It also provides parents with a much needed peer support group relating to the issue of drug dependency. Many parents have been in parent support groups when their children were younger but perhaps no longer have that outlet, and find themselves at a new stage of their lives when they are able to get some of the support they will need. Several times, when we have had only one family involved, they have mainstreamed with a hearing group. While they miss out on some of the peer support relative to the deafness issues, they will realize some important commonalities with the other families. It helps to normalize and put their own experiences in perspective.

Another area that we stress is involvement with AA/NA while in treatment, aftercare planning, and education and prevention within our local community. In Minnesota, during the last three years, we have seen a great deal of growth in the deaf recovering community. In 1987, there was only one A.A. meeting for the deaf, located in the Twin City area which was run by two older hearing gentlemen. The meeting itself had been in existence for about seven years and was founded by these two men who do not sign and an interpreter is always present. The average size of this group was about three to five members with only one year sobriety. Deaf persons would come and

go, which might be because at the start of each meeting the two hearing gentlemen would say "We are here for you, we set up this meeting for you and when we feel you are ready to take over this meeting we will let you." These gentlemen mean well, but one can see why deaf persons would feel offended and not want to return. With the help of a hearing recovering person who signed, another A.A. meeting for the deaf and run by the deaf was started. With time, patience and commitment, in about a year and a half, there were enough members that another 12 step meeting for the deaf was started. Minnesota currently has six 12 step (A.A. and N.A.) meetings in the Twin City and St. Cloud area. Interpreters are always present for those who are hearing, hard-of-hearing and do not sign and also for the Deaf-Blind members. We make sure that hearing people are not excluded, because most deaf people are new in recovery and need to learn from those with experience.

The 12 step program philosophy is of a "spiritual base." One aspect of spirituality is the feeling or sense of purpose, meaning and hope in one's life. It is crucial that in order for deaf persons to achieve this sense of hope, they must have exposure to Deaf recovering role models. Spirituality is important as well as fellowship in order for sharing, growth and change to happen in recovery. Until recently, Deaf persons were often excluded from "fellowship" due to barriers in communication. Giving up the liquor and drugs will leave you dry but communication will open the doors to recovery. In Minnesota, our Deaf recovering community is growing and we have fellowship that would not have happened without commitment. The desire to stop using was strong enough and the needs of the community were important enough that it was made possible for Deaf individuals to recover along with people of other cultures.

In the Spring of 1989, when our chemical dependency program began, not only did it provide more options for treatment to Deaf and Hard-of-hearing individuals but it served as a positive impact in the deaf community. A large number of the Deaf community was present for the open house celebration. During this ceremony, two Deaf persons, one a well known leader in the community, made public to the community that they were in the recovery program and shared some of their experiences pointing out barriers they had faced which they had dealt with or overcome. This disclosure was not an easily made decision, but they felt that in order for others to overcome the barriers and learn that it is o.k. to be in recovery, that they needed to be used as deaf role models. This event sparked change within the Deaf community in many individual's feelings and attitudes towards those with chemical abuse and/or dependency problems. Where not long ago it was still considered a 'stigma' and looked down upon, now it seems to be understood, supported and accepted not only as a personal problem but as everyone's concern. (If you are not part of the solution, you are then part of the problem.)

Another component of our program has been the commitment we have shown toward education and prevention. Since the Fall of 1989, we have been going into mainstream and residential schools facilitating chemical abuse and dependency awareness classes, and groups. We have also gone into the Deaf community and provided free workshops on such topics as 'Anatomy of Addiction,' 'Chemical Dependency and Family Dysfunction,' and 'Chemical Dependency's Effects on Spiritual, Physical and Emotional Health.' The more we are in the community, the more that is learned, the more risks that are taken and the more the Deaf community begins to share without fear of being labeled or outcasted. Community support is important to any person and program. Without it, change and progress are not possible.

Another issue that we have had to deal with, is aftercare placement. Over 75% of our referrals have been from out of state where no services for the hearing impaired exist. We were

fortunate to have access to an Extended Care Program that was willing to work with hearing impaired clients. Granville is licensed as both an extended care and half way residential program. They have a house for women and another for men who are at least 16 years of age with a 3-6 month average length of stay. Interpreter services are provided for at least 15 hours a week, and their counselor has had experience working with other Deaf clients. We offer their staff weekly sign language classes and have acted as consultants to them since the Fall of 1989. When funding is not available, we work with each state to access existing services.

When the Minnesota Chemical Dependency Program for Deaf and Hard-of-hearing Individuals began, a needs assessment was completed on a national basis which indicated the necessity for a program exclusively for hearing impaired individuals. Problems arose during the past year that the needs assessment did not indicate:

- The field of deafness is approximately 10-20 years behind in terms of recognition and acceptance of chemical dependency as a problem.
- Many professionals in the field of deafness have never referred a client for chemical dependency treatment, and don't know what the criteria is, or the procedures.
- Mental health professionals and teachers can be caretakers, and want to "care for" their own clients.
- Schools have a fear that if they refer a student for chemical dependency treatment that they will be financially responsible.
- 5) A market survey that we completed was directed toward professionals who work with Deaf clients. They were asked if they would refer to a program specifically for the

hearing impaired. These people are not the ones who control state money if the referrals are on public assistance.

- 6) Most professionals stated they would refer clients to a chemical dependency program designed for the hearing impaired, but in reviewing the survey, many had not successfully placed many, if any clients.
- There is a shortage of professionals trained in the area of deafness and chemical dependency.
- 8) People want to keep funds within their own state, and would prefer to set up their own inpatient C.D. program. Just because surveys done in each state may indicate the need and potential for referrals, it does not guarantee they will be willing to enter treatment.

Discrimination oftentimes exists during the referral process because the assessors have never dealt with a hearing impaired client, and they tend to think the process should be handled differently then with a hearing individual. For example, when a hearing person from New York was referred for treatment in our hospital, it took 3-5 days. Some of our Deaf/Hard of hearing clients on public funds have taken 2 to 3 months! Instead of requiring only a chemical assessment, which is required of hearing referrals, an audiological examination, psychosocial history, speech and language assessment is also required. The referral process is further complicated because most of the assessors are not fluent in American Sign Language.

Through our experience working with the referral process throughout the United States, it has become quite clear that we currently don't have the funding mechanisms and numbers in place to justify each state having their own inpatient treatment program. We feel that you can refer clients out of state for inpatient treatment program, but you can't for aftercare. We would like to see states focus on securing funding for aftercare programming and school intervention. In the future we need to regionalize inpatient treatment programs if any of them are going to be successful financially and programmatically. We have found out that it is extremely expensive to provide a quality inpatient chemical dependency program to hearing impaired individuals. Currently, if each state tries to start their own inpatient C.D. program, they will all fail because the number of referrals and funding are not there to support it. There are very few existing halfway or extended care facilities available for hearing impaired individuals. One of the only outpatient programs exclusively for hearing impaired exists in Texas. We need to work together to have the Drug problem in America become a focus for the Deaf Community. Chemical dependency is not mentioned in national reports listing priorities within the field of deafness. As professionals, it is our responsibility to educate our colleagues within this field about their need to address this important and neglected issue. The most powerful tool in bringing about this support and change is education which can be done both formally and informally. The Deaf recovering community is at a place where the general hearing recovering community was a few decades ago. With time, patience and commitment the deaf recovering community will grow and prosper nationwide. Minnesota is proving that this is not just a dream, but a reality.

Chemical dependency is grounded in the Deaf culture. Treatment is needed and must be designed by persons who live in the deaf community and/or have extensive, specialized training in the psychological, social, and communication needs of members of that community who are chemically dependent. Knowledge about the special needs of Deaf/Hard of hearing persons in CD treatment will become important only when it is derived from a model program that has the trust of both the Deaf community and the CD treatment providers who serve them.