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HIV/AIDS prevention education: Policies and procedures for the developmentally disabled.

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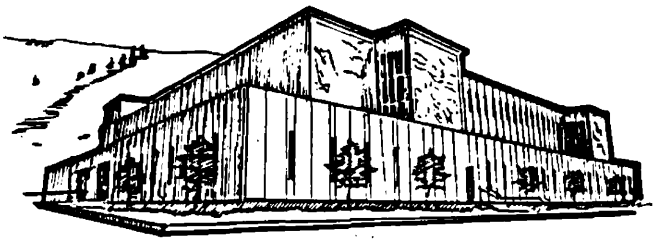

HIV/AIDS PREVENTION EDUCATION, POLICIES AND PROCEDURES FOR THE DEVELOPMENTALLY DISABLED

by

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I.1 Introduction to the Problem

The subject of HIV/AIDS has caused increasing alarm for the general populace throughout the nation. As of July, 1989, the Centers for Disease Control reported that there were 102,621 cases of AIDS among adults and children. This figure is a 49% increase over the same period in 1988, for which 69,085 cases were identified. It is currently estimated that 1.0 to 1.5 million persons are infected with the HIV virus. The incidence rate for diagnosed AIDS cases is highest in New York, California, and Florida. The five U.S. cities with the highest rates of occurrence are New York City, San Francisco, Los Angeles, Houston, and Miami. While HIV/AIDS infection is generally seen as an urban metropolitan area crisis, even in a rural state such as Montana, numerous cases have appeared, the majority of those cases derived through sexual contact within high risk groups of individuals. The average incubation period for AIDS ranges from 5 to 10 years before recognizable symptoms can be identified. Thus it is entirely likely that individuals have contracted the disease in major population centers up to 10 years previously, and since moved to rural communities, making the AIDS/HIV epidemic everybody's problem.

I.2 The Problem Within the Developmentally Disabled Population

As an effect of deinstitutionalization, the developmentally disabled population in Montana has experienced increased involvement in community-based residential

services, activities, and public schools. As concerns have escalated about AIDS within the general population, there is also an increasing probability that it is only a matter of time before HIV/AIDS related problems will arise within the group of persons with developmental disabilities as well. It is crucial that steps be taken to prevent both the spread of the disease within this group, and societal regression leading to increased segregation and discrimination for these individuals, setting back the clock on the deinstitutionalization movement. To address this issue proactively, it is critical that quality prevention education for this population be established, and appropriate procedural responses be formulated to address "worst case" circumstances should they arise.

I.3 Individuals Requiring Attention

The range of individuals to be addressed regarding HIV/AIDS infection and persons with developmental disabilities falls into five groupings for special consideration:

1. Children with congenital infection, largely infants and toddlers with delayed development or loss of developmental achievement.
2. Children with acquired infection from blood products, including those with hemophilia, in all stages of childhood and adult life.
3. Adults with developmental disabilities, including mental retardation, living in the community, who may have already acquired the infection and who present an ongoing challenge in program management.

4. Youth and adults with developmental disabilities, including mental retardation, who require special educational assistance to avoid contracting AIDS, especially during sexual activity.

5. Primary care providers, school personnel and other staff, who are uncertain about their own risks regarding infection from persons with disabilities and who have other special needs (NY OMRDD, 1989).

Preventative vaccines or curative drugs are estimated to be years away and prevention education is the primary tool available to withstand this lethal assault. This report is primarily oriented to prevention educational materials for the developmentally disabled. During the course of the ensuing discussion however, attention is directed to each of the five categories indicated above because at many points they are all interrelated elements of the same problem, and materials on virtually all aspects were provided by respondents.

I.4 AIDS and HIV Defined

It is important to distinguish between Acquired Immune Deficiency Syndrome (AIDS) and the Human Immunodeficiency Virus (HIV) which causes AIDS. According to medical authorities, AIDS cannot be spread from one person to another, but HIV can be passed to other people through specific body fluids. A person with HIV infection can have no outward symptoms of the illness. HIV infection refers to all people with the virus, while AIDS refers only to those in the final stage of HIV infection who have specific illnesses and conditions. In recognition

of changing medical terminology, newly-enacted statutes generally refer to HIV infection rather than AIDS (Rennert, Parry, & Horowitz, 1989).

I.5 HIV/AIDS Prevention in the General Population

In the absence of a vaccine or cure, virtually all medical experts believe that education about prevention of the spread of the virus that causes AIDS is society's strongest weapon -- both against the disease and against AIDS panic. Most of the literature suggests that the goal of an AIDS education program should be not only to inform persons of the imminent dangers of the virus, but also to integrate the information into a much broader context of learning which addresses self care, self-esteem, and making responsible decisions about one's self and one's interpersonal relationships.

The major component of AIDS prevention consequently, is transfer of knowledge, creating an informed public, with particular emphasis on high risk groups of individuals. In general, AIDS is not viewed as a serious threat in Montana. A survey conducted in relatively rural Kentucky by Dhooper and Royse (1989) found that respondents living in rural communities were found to be less informed about AIDS, and less accepting of homosexuals and children with AIDS than their small town and urban counterparts. Their study suggests that rural areas of our country, while not immune from HIV/AIDS related problems, are in need of novel approaches to informing and educating the general populace as a major step in the prevention process.

II. THE EXTENT OF THE PROBLEM: HIV/AIDS AMONG PERSONS WITH DEVELOPMENTAL DISABILITIES AND MENTAL RETARDATION

II.1 Children With Congenital HIV Infection

As mentioned, there are 5 groupings of individuals within the community of persons with developmental disabilities requiring special consideration. The first group, children with congenital HIV infection, is unfortunately the largest and fastest growing sub-population affected by the AIDS/HIV epidemic. They are certainly the most difficult to address with a preventative approach from within the framework of developmental disabilities services.

An alarming number of children are being born each year diagnosed as HIV positive. In April, 1987, the incidence of congenital infection among children under 13 years of age was estimated at 471 reported cases. Among children aged 13 to 19, the reported cases numbered 139. The nearly 500 cases among young children was double the number of cases reported a year earlier, and nearly 60% of those children had died (Koop, 1987).

In August, 1988, 917 children under the age of 5 were diagnosed as having AIDS, and 1095 children under the age of 12 were identified. In the age range from 13 to 19 years, 282 persons were diagnosed as having AIDS (Crocker & Cohen, 1988). Both of the more recent figures represent more than a two-fold increase in the numbers of children with AIDS in a year and a half, with 57% of the children having died at that point in time.

In July, 1989, CDC reported that 1,736 children under the age of 13 were infected with AIDS, another increase of 57% from the previous year. It was anticipated by the Public Health Service in 1987, that the number of reported AIDS cases by 1991 would be 3,000 children, and virtually all of them will die. The larger concern is that those figures reflect only reported AIDS cases. As of November, 1989, public health officials and medical experts estimate that by 1991 there will be 20,000 children who will be HIV positive (Association of Administrators of the Interstate Compact on Adoption and Medical Assistance, Inc., 1989).

This astonishing increase in incidence rate among children can be attributed to both the dramatically escalating AIDS epidemic, and to an increased rate of identification and reporting with heightened public awareness in the area of congenital HIV infection. Tragically, almost all children with congenital HIV infection manifest evidence of central nervous system dysfunction and the vast majority show signs of developmental delay or loss, mental retardation, or cerebral palsy. If HIV infection continues to spread in children as estimated, AIDS could become the leading infectious cause of mental retardation and brain damage in children.

Some children, especially those with hemophilia, were infected by blood products. However, the vast majority of the infected children are offspring of intravenous drug users or their sexual partners. As a result, prevention education must be aimed at that high risk group as virtually the only means to prevent this tragedy from escalating.

II.2 HIV/AIDS Infection Within the General Developmentally Disabled Population

There is increasing concern nationally that the AIDS virus will become a problem within the general community of persons with developmental disabilities. There is no conclusive data to indicate the level of vulnerability of persons with developmental disabilities to contracting the AIDS virus. Stiggall (1988) suggests that the risk may be higher than we might anticipate. However, as indicated in the 1989 American Journal of Public Health, a national survey of state developmental disability agencies by Marchetti, et.al., reported a national total of only 45 HIV positive cases, 31 of them in institutions, and 14 in community programs. These were reported by 11 of the 44 states responding to the survey (Marchetti, et.al., 1989). Unfortunately, those numbers are considered an under estimation in relation to the actual extent of the problem because, (1) the respondents provided the information voluntarily, (2) no systematic attempt has been made in any of the states to screen adult clients, suggesting other infected clients are undoubtedly present, and (3) the lack of any reliable reporting mechanism between community providers and state service systems suggests that additional adult clients known to community providers to be infected may not have been reported to state agencies (Kastner, et.al., 1989).

In the previous discussion regarding congenital HIV infection, the incidence figures exhibit a dramatic increase in a relatively brief period of time. A portion of the increase can be an effect of heightened public awareness and increased reporting of cases. The other, more alarming cause for escalation is directly related to the epidemic nature of the disease. Given those circumstances, it should be anticipated

that the incidence rate among the general population of persons with developmental disabilities will follow a similar pattern as public and agency consciousness of the potential problem is raised.

II.3 Risks to Persons with Developmental Disabilities

The handicapping conditions of persons with developmental disabilities can encompass a number of risk factors not usually found within the general population. As a result, the group of individuals addressed in this discussion has the potential to be a high risk group for contracting the virus. The following points stand out regarding risk factors for persons with developmental disabilities and the AIDS virus:

1. Contrary to many misconceptions, this is a sexually active group of individuals - especially during adolescence in the high school years, and among individuals residing in independent or semi-independent living situations.
2. Reading skills are typically limited, so obtaining information from magazines, books or brochures is difficult. Because of difficulties regarding judgement and discrimination skills, separating fact from fantasy in media, hard for all of us, is even more difficult for these individuals. As a result, this population often requires additional specialized training to acquire basic concepts.
3. Many in this group are less aware of physical concerns than other individuals. They may have symptoms of sexually transmitted diseases (STD) that they are not aware of. If these symptoms go unnoticed and unreported, and the STD is not diagnosed, the fact that this individual is engaging in risk behavior may go unnoticed, and valuable opportunities for prevention education may be lost.

4. The risks imposed by group or institutional living and the historical problems faced in effectively controlling epidemic diseases in such settings can compound the concerns regarding STD's. Proper care with body fluids protects against the spread of infections like hepatitis or HIV, but these precautions must be effectively monitored in the institution.

5. There may also be shared sexual partners in group living environments, which could increase risk.

6. Poor self esteem is another factor contributing to the vulnerability of this group. This places them at greater risk than their nondisabled counterparts to be sexually abused or exploited (Blomberg, 1986), and may lead to drug use and/or multiple sexual partners, both high risk activities.

7. Many individuals have little impulse control or understanding of activities suggested to them. If they are invited to share drugs or offered money for sexual favors, they may eagerly comply as a way to feel accepted.

8. Another factor markedly increasing the risks for this group of individuals is sexual abuse. According to a recent study by Susan Hard, it was found that the rate of sexual assault of females with developmental disabilities was 83 percent, and 32 percent among males. Other studies have found a sexual abuse rate to be even higher (Planned Parenthood of Sacramento Valley, 1988).

Unfortunately, as disabled individuals are integrated into the community, they become exposed to and perhaps involved with the unhealthy habits of some nondisabled citizens (Stiggall, 1988).

III. CURRENT STATUS OF MONTANA HIV/AIDS PREVENTION EDUCATION, POLICIES AND PROCEDURES REGARDING PERSONS WITH DEVELOPMENTAL DISABILITIES

III.1 APP/MDDP Survey Regarding AIDS/HIV Prevention Education, Policies and Procedures in Montana

The AIDS Prevention Project for Montana's Developmentally Disabled Population (APP/MDDP) conducted a survey within Montana regarding HIV/AIDS prevention education, policies and procedures. One purpose of the survey was to review and analyze client educational materials in use to prevent the spread of the HIV/AIDS virus among persons with developmental disabilities living in community-based residential settings. In addition, the administrative policies and procedures in place were reviewed.

In this section the status of educational programming, policies and procedures in use in programs that responded to the survey are addressed. Information has been gathered through mailed surveys sent out in October, 1989 to 41 primary agencies in Montana providing community based services to persons with developmental disabilities. Additionally, information was gathered from the following state agencies in Montana:

- Developmental Disabilities Division
- Department of Health and Environmental Sciences HIV/AIDS prevention office
- Office of Public Instruction HIV/AIDS coordinator's office

In the survey to the provider agencies, the questions posed for their response regarding HIV prevention educational materials were:

1. Does your agency have educational materials, policies and procedures either in place or in draft form, addressing AIDS prevention and the developmentally disabled?
2. If so, would it be possible for you to provide me with a brief description of the prevention education materials which are in use, or planned for use in your state?
3. If your agency has policies and procedures in use or in draft form, would it be possible for you to provide me with copies of those?
4. If your agency does not have HIV/AIDS prevention materials, policies or procedures drafted at this time, do you know of such materials available through other agencies, or through other national sources? If so, could you provide me with a contact person name and address, or refer a copy of this request on to them?

III.2 APP/MDDP Community Based Provider Survey Results - Prevention Education, Policies and Procedures

Of the 41 provider agencies polled, 13 (32%) of the agencies responded to the inquiries. Generally, the provider agencies responding were Montana's larger private non-profit corporations located in the states largest cities where the prevalence of HIV infection is more of a problem. It is assumed that the smaller, more rurally

located corporations were not responding to the survey at least partially due to the lesser degree of perceived threat from the HIV virus in those settings. At this time, two of the agencies responding (15%) have an HIV prevention educational program for their developmentally disabled clients, relying on instruction by the local Family Planning office and supplemental materials from the Training Resource and Information Center (TRIC). Two of the 13 responding agencies have some form of staff training in place. Four of the 13 programs responding (31%) have some form of policy or procedure in place addressing some aspect of HIV management and persons with developmental disabilities. Specifically, the aspects addressed by the five agencies responding affirmatively are summarized by agency as follows:

1. Special Training for Exceptional People (STEP), Billings, MT. -

   A brief paragraph in their Health Prevention Policy addresses testing of individuals suspected of having HIV infection.

2. Helena Industries, Inc., Helena, MT. -

   The Agency has an HIV Employment Policy Statement.

   Staff receive instruction in preventative procedures.

   Client education utilizes the State of Montana Training Resource and Information Center (TRIC) library materials, and demonstrations by the Lewis and Clark County Health Department and local Family Planning services. Clients are referred by their Individual Habilitation Planning team.

3. Opportunity Industries, Inc., Missoula, MT -

   AIDS prevention or response policies are incorporated in OII policy on Health. Staff receive instruction in symptoms, transmission, and control of AIDS. No clearly defined instructional program is in place for clients.

4. Billings Workshop, Inc., Billings, MT -

   Has policies in place regarding admittance of clients with HIV infection to the program. Policies in place regarding employment of staff with HIV infection. A brief policy describes methods for avoidance of transmission of HIV virus. No specific developed client prevention education program.

5. Billings Training Industries, Billings, MT -

   Specific policies not in place at this time. Utilize local Family Planning services for training of clients in HIV prevention.

The other community based programs responding to the survey serving persons with developmental disabilities have not initiated any HIV prevention educational programs. Nor have they developed policies or procedures to prevent transmission of infection or provide guidance in response to cases of HIV infection.

III.3 APP/MDDP State Agency Survey Results - Prevention Education, Policies and Procedures

On the state agency level, the Developmental Disabilities Division (DDD) utilizes a comprehensive AIDS Trainer's Guide and program developed for Division staff. This training guide was developed as a cooperative effort by the Montana

Department of Administration, State Personnel Division, and the Department of Health and Environmental Sciences AIDS Program. The format and some selected content of the New York State Department of Social Services, AIDS Trainer's Guide was adapted in development of this document. All DDD staff receive training based on this set of information. At this time, DDD does not have policies or procedures in place regarding HIV transmission prevention, or agency response to identification of HIV infection within the developmentally disabled population. A prevention education program is not currently available from DDD at this time, either addressing clients with disabilities receiving services, or direct care staff.

The Office of Public Instruction has developed the Montana AIDS: Curriculum Planning Guidelines. This serves as a thoroughly useful set of generic prevention education guidelines for public school systems. However, it does not specifically address the unique learning needs of individuals with developmental disabilities. Similarly, the Montana Department of Health and Environmental Sciences has developed procedural guidelines addressing prevention within the general population. While the guidelines serve to address the fundamental procedures and issues involved within the domain of HIV prevention, once again, the unique learning needs of individuals with developmental disabilities are not dealt with to any degree.

III.4 Summary

As demonstrated in the preceding sections, the service system in place in the state of Montana for the developmentally disabled is seriously lacking in the area of

prevention education either for staff or clients. Nor do the community-based programs or the state agencies have in place any comprehensive array of policies or procedures addressing prevention of the spread of HIV infection within this population. Another serious area as yet unaddressed in any systematic statewide manner involves the procedures and a philosophical orientation to be followed when a person with a developmental disability has been diagnosed as having HIV infection.

The findings from this survey are not particularly unexpected. There is a relatively low identified incidence rate of the HIV virus in the general population in Montana at this time. That factor combined with the presumed non-occurrence of the virus within the population with developmental disabilities suggests that it is only logical that there has been less emphasis placed on HIV prevention. As noted in previous discussion in *II.3 Risks to persons with developmental disabilities* it is entirely likely that the extent of the risks, and possibly the extent of the problem has been seriously underestimated.

IV. CURRENT NATIONAL STATUS OF HIV/AIDS PREVENTION EDUCATION

IV.1 APP/MDDP National Survey Regarding AIDS/HIV Prevention Education

Given the above issues and concerns, the AIDS Prevention Project for Montana's Developmentally Disabled Population (APP/MDDP) was formed to conduct a national survey regarding HIV/AIDS prevention education, policies and procedures. One purpose of the project was to review and analyze client educational materials in use nationally to prevent the spread of the HIV/AIDS virus among developmentally disabled populations living in community-based residential settings. In addition, the administrative policies and procedures in place in other states were reviewed for possible adoption in Montana.

In this section the status of educational programming in use in states that responded to the survey mailed to state agencies in October, 1989 is addressed. Information has been gathered through mailed surveys sent out to agencies in all 50 states. The state units surveyed are counter-parts to the following agencies in Montana:

- Developmental Disabilities Division
- Department of Health State HIV/AIDS prevention office
- Office of Public Instruction HIV/AIDS coordinator's office

In the survey, the questions posed for their response regarding HIV prevention educational materials were:

1. Does your agency or other agencies in your state have educational materials, either in place or in draft form, addressing AIDS prevention and the developmentally disabled?
2. If so, would it be possible for you to provide me with a brief description of the prevention education materials which are in use, or planned for use in you state?
3. If your agency does not have HIV/AIDS prevention educational materials at this time, do you know of such materials available through other agencies in your state, or through other national sources? If so, could you provide me with a contact person name and address, or refer a copy of this request on to them?

IV.2 APP/MDDP Survey Results - Prevention Education

Of the 50 states polled, at least one agency from each of 43 (86%) of the states responded to the inquiry. From 17 states (34%), two or more state agencies responded to the inquiry, with all three agencies responding from 2 states, Utah and Louisiana. The following tables contain a brief summary of the responses from the 42 states replying to the survey. The states providing additional information or materials of value are denoted by a (*) next to the response. Following the table is a summary listing regarding the additional information or material provided, separated out by state.

TABLE 1

SUMMARY OF STATES RESPONDING TO APP/MDDP SURVEY:

PREVENTION EDUCATION FOR DEVELOPMENTALLY DISABLED

ED. DEPT.	DEPT. of HEALTH	MR/DD AGENCY	TOTALS
NO: 10	NO: 22	NO: 22	NO: 54 (89%)
YES: 4	YES: 0	YES: 3	YES: 7 (11%)
TTL: 14	TTL: 22	TTL: 25	TTL: 61

43 states responding

TABLE 2

Statewide AIDS Prevention Education Program for MR/DD Population

STATE	ED. DEPT.	DEPT. OF HEALTH	MR/DD AGENCY
Alabama			NO
Arizona	NO	NO	
Arkansas			NO
California		NO	NO*
Connecticut			NO*
Delaware		NO	NO
Florida			NO*
Georgia		NO	
Hawaii		NO	
Idaho	NO	NO	
Illinios		NO*	
Indiana			NO
Iowa	NO		NO*
Kansas			NO
Louisiana	NO*	NO	NO*
Maine	YES		YES*
Maryland	YES*		
Massachusetts			NO*
Michigan	NO*		NO*
Minnesota		NO	
Mississippi		NO*	NO
Missouri		NO	NO*
Nebraska			NO
New Hampshire	NO		
New Jersey			NO
New Mexico	NO	NO**	
New York			NO*
North Carolina		NO	
North Dakota		NO**	NO*
Ohio			NO
Oklahoma		NO	YES***
Oregon		NO*	
Pennsylvania			NO
Rhode Island	YES*		
Tennessee		NO*	NO*
Texas		NO*	
Utah	NO*	NO*	NO
Virginia		NO*	
Washington	NO*		NO*
Washington D.C.			YES*
West Virginia	NO		
Wisconsin	YES***		NO
Wyoming		NO*	
43 States Responding	NO: 8 Yes: 5 TTL: 13	NO: 15 YES: 5 TTL: 20	NO: 13 YES: 15 TTL: 28

CHARACTERISTICS UNIQUE TO PARTICULAR STATES RESPONDING TO THE SURVEY - designated by a (*) in Table 2

AL - Ed. Dept. adapted AIDS curriculum for DD pop

CA, WA - Staff trng program

CN - other health organizations have AIDS prevention programs

FL - has HRS AIDS Manual for general population prevention

IL - developing general pop. pkg: AIDS Education Readiness Program.

IA - staff training course description

LA - Each facility addresses issue specific to clients served, Dept. of Ed. has AIDS Ed. Curriculum Guide, not DD specific

** WY, VA, TN, NM, OH, ND,MA - Loans YAI program to interested agencies, Dept. of MH & MR uses Circles & Tips.

Md - has Instructional Guidelines for AIDS Prevention Education includes section re. special ed. students

MASS - has very good staff training pkg: One Step Index System.

MO - indicates trng provided to DD persons but ex. not given

MS - Dept. of MH developing one

TN, MI, WA, UT, TX, OR - developing curriculum specific to DD population, has staff training curriculum

ND - variety of training conducted re. AIDS for DD staff training

NY - comprehensive staff training manual

OK - use Life Horizons Program (Kempton) for developmentally disabled

RI - Has Instructional Outcomes for AIDS Education, and an AIDS curriculum for use with special needs children.

UT - Has Responsible Healthy Lifestyles: Teacher Resource File for AIDS Education. Appears to be very good for general population.

DC - MRDDA HIV/AIDS Education-Identification- Intervention Program, copy not included

*** WI - has Instruction about AIDS in Wisconsin Schools as a supplement to Guide to Curriculum and Planning in Health Education available through the publication sales dept.

IV.3 Comment Regarding the Table Data

In interpreting the data in the tables, it is important to bear in mind the following points:

1. The purpose of this survey was primarily to identify materials which might be available elsewhere in the nation which Montana might be able to apply to our individuals with developmental disabilities. It was thus not a stringently rigorous research project.
2. In some instances in both prevention education data tables and policy and procedure data tables, the responses provided were not totally definitive regarding the presence or absence of educational materials or policies in place in their state regarding HIV virus prevention and their developmentally disabled population. The respondent chose to address only state policies or educational materials, not addressing the other aspect of the inquiry. Some responses were therefore recorded as "NO", and represent a non-response to one aspect of the question posed.
3. Other agencies within a state that did not respond to the inquiry might have policies, procedures and/or educational materials. Because they did not respond to the survey, the tables show a lack of a state-wide educational program, policies or procedures for their state, though they may in fact have something in place but simply not reported.

4. It is important to note that this inquiry asked whether the state agency had an educational program specifically addressing the developmentally disabled population. Several states indicated that they had very good, highly acclaimed HIV/AIDS prevention education programs for the general population, especially for school aged children. However, their materials did not address the developmentally disabled population, they were in the process of adapting their materials, or their materials were recommended as adaptable for this group. As a result, their response to the inquiry was recorded as "NO" with a (*) next to it, and reference to the materials they have in use.

V. AIDS PREVENTION EDUCATION FOR PERSONS WITH DEVELOPMENTAL DISABILITIES: ANALYSIS OF THE INFORMATION

V.1 Introduction

The survey responses tabulated in the previous section graphically illustrate the minimal degree of prevention education currently utilized for the developmentally disabled population. As shown, only 11% (7 of 61) of the agencies responding to the survey indicate that they have an HIV/AIDS prevention educational program in place for this population. Of that small group, four of the seven agencies are state departments of education emphasizing prevention within the school aged population. It is encouraging to note that numerous agencies report being in the process of developing or gathering materials to address this problem.

HIV/AIDS prevention education for this group, as with the general population is in infancy stages of development. The information accumulated as a result of this survey provides a composite image of national AIDS/HIV prevention efforts, and serves as a basic core educational foundation upon which future efforts can be built. A tragic irony exists in that for years within the developmentally disabled service community, sex education in any form has been a seriously unaddressed topic of concern. This area has been frequently identified for attention, but providers traditionally avoid venturing into the moral and social complexities of the broader sex education context. As Stiggall (1988) points out however, the fear of AIDS has created an environment in which sex education is "in." From schools and agencies

which formerly banished sex education as too controversial we are now hearing cries for help.

V.2 Curriculum Context

The majority of the literature suggests that the goal of an effective HIV/AIDS education program should be not only to inform individuals of the imminent dangers of the virus, but also to integrate the information into a much broader context of learning which guides an individual toward avoidance of dangerous behaviors, based on the best knowledge available about modes of transmission (sex, IV drug use). Two major challenges presented by the instructional content and ultimate goal are: (1) the learning difficulties of the population we specifically address in this discussion and (2) the necessity of the highest quality, most successful teaching strategies available given the life or death consequences for not providing adequate instruction.

To be effective, the needed education should not come as an isolated unit on AIDS. As pointed out by the Centers for Disease Control (CDC), education about AIDS may be most appropriate and effective when carried out within a more comprehensive health education program that establishes a foundation for understanding the relationships between personal behavior and health. As an example, education about AIDS may be more effective when individuals at appropriate ages are more knowledgeable about sexually transmitted diseases, drug abuse, and community health (CDC, 1988).

Education should be a part of a comprehensive, positive family life/sex education program. Human sexuality is a part of life. Being taught only about a tragic virus that can be acquired as a result of a sexual act would reflect a slanted, negative impression of sexuality. AIDS education insensitively offered may create unnecessary fear and distress. Educators must strive for balance: present factual information, be explicit and honest. One should not teach in a manner that frightens, engenders paranoia, or promotes homophobia. Incorporating this critical education about AIDS in a positive family life education framework sets the stage for maintaining this balance (Stiggall, 1988).

V.3 Curriculum Components

In developing an AIDS instructional program, there are four basic concepts of AIDS education to address as follows:

1. There are some diseases that are communicable diseases. AIDS is a communicable disease.
2. There are decision-making and refusal skills to practice that will lead to a healthful lifestyle, and there are methods of prevention for AIDS.
3. There are social and economic implications of AIDS.
4. There are community resources for information, help, and counseling.

When deciding how these concepts will be addressed, it will be necessary to consider whether or not similar objectives are already being addressed in a health

education program. For example, young students or adults with more extreme disabilities may be learning how to establish good health practices (such as hand washing) in their daily routines. Older students or adults with less involved handicaps may be learning about the effects of alcohol, tobacco, and other drug substances. These objectives within health education can be used to introduce -- and/or expanded to include -- some objectives related to AIDS prevention (South Dakota Dept. of Education and Cultural Affairs, 1988).

Prevention education for persons with developmental disabilities, as for all people needs to include four basic components:

1. A clear message that AIDS is dangerous.
2. That it can happen to you.
3. A person can have AIDS and not know it.
4. You can prevent AIDS. (Stiggal, 1988)

To assist young people in understanding these four concepts, classes should include the following topics:

1. reproductive anatomy;
2. how one can and cannot contract the virus;
3. information about relationships, values and decision making;
4. skills in assertiveness;
5. the possibility of choosing abstinence;
6. how to prevent sexual abuse;

7. where and how to obtain and use condoms;
8. what the antibody test means and where to go for testing, counseling, treatment;
9. what an individual's rights and responsibilities are;
10. the meaning of informed consent. (Stiggall, 1988)

The points outlined above for inclusion in an effective program serve as an excellent basis for whatever HIV/AIDS Prevention Education program might be selected or developed for persons with developmental disabilities.

V.4 Adaptations for the Developmentally Disabled

Winifred Kempton was the first to outline specific techniques necessary for teaching sex education to persons with disabilities that hinder learning (Kempton, 1988). Her work and the work of those who have followed help us know that for such education to be effective it must meet several criteria.

1. Teachers should "draw out" from the students what they already know, to assess understanding and areas of interest.
2. Statements, messages and materials should be as real, as concrete, and explicit as possible.
3. Teaching approaches must not rely on reading skills in imparting information. Audiovisual materials, models and pictures are essential and effective.
4. Learning should take place over a longer period of time, with short sessions offered over several different days.

5. Teachers should allow for repetition and use simple language.
6. Lessons should include the opportunity to practice saying no, talking about lower risk practices, etc. through role plays.
7. Lessons should include ways to check learning and get feedback from students.
8. Materials should be as practical and relevant as possible to the learner's life experiences.
9. The education should be offered in a nonjudgmental manner.

(Stiggall, 1988)

While these may be sound teaching techniques for all students, they are absolutely essential for people who do most of their learning by means other than reading. Emphasis must be on practical and behavioral matters rather than on understanding the medical make-up of HIV (Stiggall, 1988).

As awareness and educational program development regarding sexuality and health instruction for students with developmental disabilities has increased, so have the opportunities for including AIDS/HIV prevention within their curriculum as well. It is recommended that AIDS instruction occur in a small group setting, with ample time allowed for questions and discussion. The nature of the content does not make a large group setting advisable.

V.5 Steps in the Process for Developing and Implementing an AIDS/HIV Prevention Education Plan

The nature and content of AIDS/HIV instruction in schools requires a larger and more diverse group to be involved in curriculum planning than ever before, and

ultimately the local board of education has the final authority to approve all programs. Nevertheless, there are common procedures to be followed in the development of curriculum for any subject. The steps for undertaking this process for AIDS/HIV education are as follows:

1. Designate an AIDS Advisory Council
2. Review current materials (State Board regulations, Office of Public Instruction Policies, related materials currently in use in district)
3. Conduct a needs assessment and establish priorities
4. Identify resources (school and community)
5. Develop an AIDS instructional philosophy
6. Develop an AIDS instructional program
7. Conduct community awareness activities
8. Conduct staff training
9. Implement the AIDS instructional program
10. Evaluate, update, and revise the program

An AIDS education program deals with complex societal and personal values and issues; and discussion about an AIDS instructional program may touch on personal, religious, cultural, and moral perspectives. So initial and continuous communication on all aspects of the intended program are of the utmost importance. The process of developing an AIDS education program requires time, cooperation, and the participation of many people from the school, the agency, the home, and the

community (South Dakota Dept. of Education and Cultural Affairs, 1988).

V.6 Evaluation of AIDS/HIV Education Curriculum and Materials for Special Needs Populations

As an educational program is being developed it is a necessity to evaluate the strengths of a number of key components. Components of importance for consideration when developing a successful AIDS/HIV prevention education program for special populations are as follows:

1. Are parents, persons with disabilities, health professionals, and appropriate community representatives involved in developing, field-testing, implementing, and assessing the program?
2. Is the program implemented as an integral part of a comprehensive health education program?
3. If a comprehensive health education program is not in place, will the AIDS education program be comprehensive?
4. Does the program fairly represent the values and mores of the community?
5. Is the program clearly communicated to both staff and community?
6. Is adequate training provided for those responsible for instruction about AIDS, including school administrators, teachers, agency staff, nurses and counselors?
7. In school programs, is the program taught by regular classroom teachers at the elementary level, and by teachers who are trained and qualified at the secondary level?

8. Is the program designed to help teenage students with developmental disabilities recognize the need to avoid specific behaviors that increase the risk of contracting AIDS?

9. Does the program describe and stress the benefits of abstinence for young people, and mutually monogamous relationships for adults?

10. Is the program designed to help persons with disabilities acquire essential knowledge and skills to protect themselves from the risk of contracting AIDS if they are sexually active?

11. Is the program designed to help individuals acquire essential knowledge and skills to protect themselves from becoming drug abusers or to protect themselves from the risk of contracting AIDS if they are drug abusers?

12. Is the program sensitive to young people's and persons with disabilities stages of psycho-social development with careful attention to ethno-cultural differences among students?

13. Are sufficient program development time, classroom time, and instructional materials provided for education about AIDS?

14. Is someone assigned to monitor the most recent medical data to keep the program up to date with current developments?

15. Is there adequate financial support to ensure continuation of the program?

16. Is there a process established for conducting this evaluation?

VI. NATIONAL STATUS OF POLICIES AND PROCEDURES ADDRESSING HIV/AIDS AND THE DEVELOPMENTALLY DISABLED

VI.1 The Need for Adequate Policies and Procedures

For a significant number of persons with developmental disabilities much of the responsibility for addressing prevention of HIV infection rests with the systems in place to provide services and assistance for them. Those systems include public schools, state developmental disability agencies, social services agencies, and community providers. Because of the enormity of the responsibility that falls upon those systems, it is imperative that they develop AIDS education programs, policies and procedures, both as preventative measures, and as strategies for managing and containing the problem when it arises.

VI.2 APP/MDDP National Survey Regarding AIDS/HIV Policies and Procedures

To facilitate in addressing the above issues and concerns, the APP/MDDP surveyed agencies in the other 49 states regarding administrative policies and procedures in place in their states related to HIV/AIDS infection and the developmentally disabled. The state units surveyed are counter-parts to the following agencies in Montana:

- Developmental Disabilities Division
- Department of Health State HIV/AIDS prevention office
- Office of Public Instruction HIV/AIDS coordinator's office

Of the 50 states polled, at least one agency from each of 43 (86%) of the states responded to the inquiry. From 17 states (34%), two or more state agencies responded to the inquiry, with all three agencies responding from 2 states, Utah and Louisiana. In the survey, the questions posed for their response regarding HIV policies and procedures were:

1. Does your agency or other agencies in your state have policies and procedures either in place or in draft form, addressing AIDS prevention and management for the developmentally disabled?
2. If your agency has policies and procedures in use or in draft form, would it be possible for you to provide me with copies of those?
3. If your agency does not have HIV/AIDS prevention and management policies or procedures drafted at this time, do you know of such materials available through other agencies in your state, or through other national sources? If so, could you provide me with a contact person name and address, or refer a copy of this request on to them?

VI.3 APP/MDDP Survey Results - Policies and Procedures

The status of policies and procedures in use in states that responded to the survey mailed in October, 1989 is presented in the following tables and discussion. Table 4 contains an unprocessed listing of the responses from the 43 states responding to the survey.

TABLE 3

SUMMARY OF STATES RESPONDING TO APP/MDDP SURVEY:

POLICIES AND PROCEDURES FOR DEVELOPMENTALLY DISABLED

ED. DEPT.	DEPT. of HEALTH	MR/DD AGENCY	TOTAL
NO: 8	NO: 15	NO: 12	NO: 35 (57%)
YES: 5	YES: 5	YES: 16	YES: 26 (43%)
TTL: 13	TTL: 20	TTL: 28	TTL: 61

TABLE 4

Statewide AIDS Prevention Policies and Procedures for MR/DD Population

STATE	ED. DEPT.	DEPT. OF HEALTH	MR/DD AGENCY
Alabama		NO	
Arizona	NO	YES	
Arkansas			YES
California		NO	YES
Connecticut			NO
Delaware			NO
Florida			YES
Georgia			NO
Hawaii		NO	
Idaho	NO	NO	
Illinois		NO	
Indiana			YES
Iowa			YES
Kansas			NO
Louisiana	YES	YES	NO
Maine	NO		NO
Maryland	NO		
Massachusetts			YES
Michigan	YES		YES
Minnesota		NO	
Mississippi		NO	YES
Missouri		NO	YES
Nebraska			NO
New Hampshire	NO		
New Jersey			NO
New Mexico	NO	NO	
New York			YES
North Carolina		YES	YES
North Dakota		NO	NO
Ohio			NO
Oklahoma		NO	NO
Oregon		NO	
Pennsylvania			YES
Rhode Island	YES		
Tennessee		YES	YES
Texas		NO	
Utah	NO	NO	YES
Virginia		YES	
Washington	NO		YES
Washington D.C.			YES
West Virginia	YES		
Wisconsin	YES		NO
Wyoming		NO	
	NO: 8	NO: 15	NO: 12
	YES: 5	YES: 5	Yes: 16
	TTL: 13	TTL: 20	TTL: 61

TOTAL:

NO: 35 (57%)
YES: 26 (43%)
TTL: 61

VI.4 Comments Regarding Table 2 Data

As discussed in the Comments Regarding Table 2 Data, in interpreting the data in the tables, it is important to bear in mind the following:

1. The purpose of this survey was primarily to identify available policies and procedures. It was thus not a stringently rigorous research project.
2. In some instances the Table 4 policy and procedure data responses provided were not totally definitive regarding the presence or absence policies in place in their state.
3. Other agencies within a state might have had policies and procedures but did not respond to the inquiry.
4. It is important to note that this inquiry asked whether the state agency had policies and procedures specifically addressing persons with developmental disabilities.

VII. HIV/AIDS PREVENTION AND MANAGEMENT POLICIES AND PROCEDURES FOR PERSONS WITH DEVELOPMENTAL DISABILITIES: REVIEW OF THE INFORMATION

VII.1 Introduction

The survey responses tabulated in the previous section illustrate a shortfall in development of prevention and management policies and procedures available to address HIV/AIDS infection within the developmentally disabled population. Less than 50% of the agencies responding indicate having HIV/AIDS prevention or management policies and procedures in place regarding the problem within this population.

The majority of the agencies, 16 of the 26 (62%) responding affirmatively, are equivalents to Montana's State Developmental Disabilities Division. Because of their residential placement responsibilities, that result is not unexpected. In particular, the state Mental Retardation/Developmental Disability (MR/DD) agencies responsible for state institutions provided relatively comprehensive packets of policies and procedures. Once again, it is encouraging to note that numerous agencies report that they are developing or gathering materials to address this problem, with many policies and procedures being provided in draft form.

The materials obtained from other states encompass a broad range of issues to be addressed regarding HIV infection and persons with developmental disabilities. As indicated in Section I.3 of this document, there are essentially 5 groupings of persons for which appropriate policies and procedures must be established.

1. Children with congenital infection
2. Children with acquired infection from blood products
3. Adults with developmental disabilities, including mental retardation who may have acquired the infection
4. Youth and adults with developmental disabilities, including mental retardation, who require prevention education
5. Health care workers, primary care providers, school personnel and other staff

The following sections address policies and procedures regarding each of those identified areas.

VII.2 Policies and Procedures Regarding Children and AIDS

The policies and procedures obtained from other states are generally applicable to both children with congenital HIV infection and those acquiring the infection through blood transfusions and other avenues. Areas addressed in the information predominantly focus around children's adoptive and foster placements. The primary issue regarding children's right to privacy and caregivers need-to-know arises repeatedly in numerous forms. One of the difficulties to be addressed involves prohibitions on revealing HIV status in photo-listings, and the effects that might have in identification of prospective foster or adoptive parents.

In the section of this report addressing the ethical dilemmas posed by the HIV epidemic and the developmentally disabled (Section VIII.), these questions are presented in more detail. Many of the questions regarding the most appropriate manner for addressing children's circumstances remain unresolved and are certainly open for discussion. Many public agency adoption and foster care specialists, however, believe the emerging state regulations and policies implemented to date afford sufficient flexibility to preclude nondisclosure when there is a need to know. A flexible policy is viewed as permitting the specialist to use professional discretion to determine when and under what circumstances to reveal positive HIV status (Association of Administrators of the Interstate Compact on Adoption and Medical Assistance, 1989).

In the Bibliography section on Policies and Procedures Materials, the third listing indicates the many useful materials obtained from other states regarding children and AIDS.

VII.3 Policies and Procedures Regarding Adults With Developmental Disabilities

The majority of the information received from other states falls into the realm of broader guidelines for management of AIDS and related conditions within the developmentally disabled community. Typically this body of information is referenced to young adults with disabilities potentially involved in high risk sexual or possibly IV drug use activities. In this regard, the policies and procedures are very similar to guidelines for the general population. To summarize, areas addressed include:

1. Detection - screening, diagnosis and special circumstances, i.e., management of aggressive individuals.
2. Issues regarding informed consent for antibody testing.
3. Confidentiality of recorded results.
4. Counseling available as needed by a patient.
5. The obligation to provide services.
6. The circumstances under which services are provided.

The Commonwealth of Pennsylvania identified eight fundamental principles addressing underlying assumptions about AIDS policies and procedures. These fairly represent the prevalent viewpoints expressed in the policies and procedures provided by other states. Pennsylvania utilizes these principles as guidelines for service policy recommendations.

Principle		Statement
1.	Non-discrimination	The human services system will serve persons with AIDS
2.	Integration of Services	The human services system will serve persons with AIDS at sites where they normally receive those services and in a routine manner.
3.	Testing	Testing for HIV will be done with informed consent and pre- and post-test counseling.

4.	Use of Test Results	The test results for HIV will not be used as a condition for service or employment.
5.	Need-to-Know	People will be informed on a "need-to-know" basis with specific rationale.
6.	Roles of Government and the Private Sector	There is a shared responsibility of the government and the private sector concerning AIDS.
7.	Accommodating Persons with AIDS	AIDS, as a catastrophic illness which affects people regardless of age, race, sex and income, is a syndrome which the human services system must accommodate.
8.	Prevention	The human services system will promote AIDS education and prevention activities.

Policies and procedures regarding AIDS prevention among adults and others with developmental disabilities falling within high risk groups are generally addressed within the context of AIDS prevention education, discussed previously in this report. However, the listing of resource materials regarding School Policies and Procedures contains materials regarding guidelines for effective school health education to prevent the spread of AIDS.

In the Bibliography section addressing Policies and Procedures Resources listings are provided which indicate the materials obtained from other states regarding

AIDS, young adults with disabilities and the general developmentally disabled population. Specific topics addressed include public schools, general policies and procedures, diagnostic information, counseling and psychological considerations, and residential placement issues.

VII.4 Policies and Procedures Regarding Emergency Medical and Public Safety Workers, Health Care Workers, Primary Care Providers, School Personnel and Other Staff

The potential risks health care workers and others face serves as perhaps a major driving force behind rapid development of adequate policies and procedures. Adequate guidelines provide a measure of assurance that caregivers and providers will not contract the disease. In turn, they also help assure that the quality of care for those in need with HIV infection will not be diminished as a result of disclosure of that information to caregivers. As would be expected then, the bulk of the policies and procedures addressing AIDS in the workplace and guidelines for emergency medical and health care workers obtained from other states predominantly focus on:

1. Universal Precautions for prevention of transmission of bloodborne HIV/AIDS infection: use of gloves and face masks; handwashing; prevention of injury from needles, scalpels, and other sharp instruments; disposal of sharp instruments.
2. Policies and procedures for reporting of detection and accidental exposure to the HIV virus.

As mentioned before, the importance of these prevention measures cannot be underrated. Even the slightest suggestion that AIDS can be acquired as a result of working with an HIV positive client could prompt sufficient alarm within the caregiver community that service quality would plummet. The U.S. Department of Labor has developed guidelines for evaluation of employer training and education programs which address both Hepatitis B Virus and HIV virus. This effort serves as a proactive measure for avoiding extreme AIDS phobia which could seriously disrupt the quality of medical and health care services we all receive.

Much of the discussion in this area centers on the facts and presently available statistics which show that the risk of contracting the disease is extremely minimal as long as the universal precautions are carefully followed. The primary emphasis for health care workers, primary care providers, school personnel, and other staff working with persons with disabilities is placed on prevention education.

In the Bibliography addressing Policies and Procedures Resources, listings indicate materials obtained from other states regarding this group. The bulk of the information is found in sections on: School Policies and Procedures; AIDS in the Workplace; and AIDS and Emergency Medical and Public Safety Workers.

VIII. ETHICAL AND LEGAL DILEMMAS POSED BY HIV/AIDS INFECTION AND THE DEVELOPMENTALLY DISABLED

VIII.1 Introduction: The Problematic Nature of AIDS and the Developmentally Disabled

In the introductory discussion of this document concerns were expressed regarding societally regressive attitudes toward persons with developmental disabilities as a side effect of the AIDS epidemic. The primary purpose of this section is to present the predominant ethical and legal dilemmas arising related to AIDS and the developmentally disabled. The resolution thereof will fall to the various systems in place to provide for the population of persons with developmental disabilities. In some instances, possible solutions or perspectives are provided, based on information provided by the American Bar Association (ABA) or other sources. At this point in the AIDS crisis, these cannot necessarily be taken as the last word in the ethical and legal discussion, as the arena in which discourse regarding AIDS takes place is a rapidly changing one.

The following subsections briefly address the five more pressing ethical and legal quandaries which the AIDS epidemic is stirring anew for persons with developmental disabilities. Not surprisingly, the majority of the issues discussed are not purely isolated to the population of persons with developmental disabilities. Rather, they are problems faced by all of society as we grapple with the crisis presented by AIDS. Regardless, due to the nature of developmentally disabled persons dependence upon the state, school systems, and provider agencies, there is a pressing responsibility for those systems to address the ethical and legal problems

as proactively as possible to avoid the serious consequences that would arise should these issues not be adequately addressed at the outset.

VIII.2 General Discriminatory Practices

As an effect of the AIDS epidemic the potential exists for increased segregation and discriminatory practices toward the developmentally disabled, turning the clock back on the deinstitutionalization movement. As pointed out by the ABA, discrimination, which always has been a problem for persons with developmental disabilities, is made worse and more complicated with the addition of HIV infection.

Often, HIV discrimination is hidden under irrational concerns about preventing transmission of the virus. Thus the potential for discrimination against persons with developmental impairments and HIV infection is two-fold. The legal challenge for the DD community is to provide needed treatment and services to all persons with developmental disabilities who have HIV infection, or are at risk of contracting the virus; and to do so in least restrictive environments that will enable individuals to achieve their developmental potential and to preserve their rights (Rennert, et.al., 1989).

The ABA indicates that persons with developmental disabilities may not be denied their rights and entitlements solely on the basis of HIV status. The basic principles of their viewpoint on the subject hold that:

1. HIV infection is a handicap.

2. According to the Rehabilitation Act of 1973, section 504 prohibits federal agencies, and programs and activities that receive federal funding from discriminating on the basis of handicap.
3. The programs identified above must provide reasonable accommodations for persons with HIV positive diagnosis.
4. Discrimination in housing based on HIV status is generally prohibited.

VIII.3 Confidentiality versus the Need-to-know

The issue of confidentiality is one of the most sensitive aspects of HIV infection. A break of confidentiality can threaten personal relationships, as well as jobs, housing, residential placement, etc. In order to retain the full trust and confidence of persons at risk, we all have an interest both in assuring that HIV related information is properly disclosed and in having clear and certain rules for the disclosure of such information. In circumstances in which persons with developmental disabilities are cared for by service providers and health care workers, this issue becomes far more complex as the providers rights to protection, and consequently their legitimate need-to-know are imposed on the clients need for confidentiality.

Clarification is needed to identify who among service and care providers has a legitimate need-to-know the HIV+ status of those who enter their systems seeking services, and to who, if at all, they may disclose that information. Three separate categories of providers must be addressed, because confidentiality constraints raise similar operational questions for each. They include:

similar operational questions for each. They include:

- non-licensed in-home workers
- foster parents
- social workers providing private and group home support

According to the ABA (Rennert, et.al., 1989), to assure adequate protection of such information, 44 states have enacted statutes specifically protecting the confidentiality of HIV test results or HIV-related information. Under these laws, health care providers cannot disclose HIV-related information about a patient or client to a third party without obtaining consent. These statutes vary as to what information is protected, but generally they prohibit disclosure of: (1) an HIV test subject's identity; (2) the test result; or (3) any information that would identify the individual.

Regardless of the confidentiality restrictions in medical records or HIV-specific statutes, all health care personnel actively involved in treating a patient, or who need information for internal administrative purposes associated with treatment, have access to a patient's medical records. No special consent from the patient is required to share this information (Rennert, et.al., 1989).

VIII.4 HIV Testing, Medical Treatment, and Informed Consent

The law requires that a physician obtain "informed consent" before they are allowed to touch anyone. To obtain informed consent requires that three elements be addressed: the consent must be competent, voluntary, and knowing.

For the consent to be competent, a person must be capable of making reasoned decisions. Such competency is not a single determination or status. Rather, an individual's competency can change depending upon the type of decision to be made. While an individual with a mental disability may be legally incompetent to enter a contract, he may have legal competence to make certain medical decisions.

The fact that an individual has a developmental disability does not, by itself, make him legally incompetent to consent to medical treatment. In fact, unless the disability affects cognitive or intellectual abilities, the disability is irrelevant to determining legal competency. For all individuals, legal competency to give informed consent to medical treatment depends on three factors: (1) the person's age, (2) the person's mental capacity, (3) the legal decision at issue (Rennert, et.al., 1989).

For consent to be voluntary, it must be freely given, based on adequate information to make a reasoned choice. Evidence of coercion, duress, undue influence, or deceit casts doubt, and possibly invalidates, a person's consent. When an individual or the decisionmaker for that person seeks the advice of a physician or other professionals in considering whether to undergo testing, those professionals must be careful not to increase the pressure, or try to coax the individual into making a particular decision.

For a person to make a knowing consent decision, they must have sufficient information upon which to base their conclusions. Two alternative standards exist to guide physicians in determining the quantity and quality of information to provide. The first standard, used in the majority of states, requires a physician to provide the level of information that other local physicians would provide under the same or similar circumstances. Some states employ a different standard, requiring the physician to provide the information that a reasonable patient requires to make an informed decision.

VIII.5 Isolation and Involuntary Civil Commitment

Kastner et. al. (1989) expresses concerns regarding a potential movement toward reinstitutionalization of persons with developmental disabilities infected with the HIV virus. In the discussion in Section II.2 HIV/AIDS Infection Within the General Developmentally Disabled Population, it is noted that of the 45 reported cases nationally, 31 of the cases were located in institutional settings, and only 14 were in community programs. Kastner, et.al. points out that such an incidence distribution runs contrary to the expected sites of origin for such a disease. Typically,

individuals would be at far higher risk for exposure to HIV/AIDS infection in community programs where involvement with persons in the mainstream of society carrying the virus is more likely to occur.

It is suggested that the incidence distribution mentioned above indicates that individuals diagnosed with HIV infection have conceivably been returned to more restrictive institutional environments. The American Bar Association (Rennert, et.al., 1989) characterizes such movement as a serious infringement of liberty which is not generally appropriate for control of spread of HIV infection. They suggest that such movement should occur only if ordered by a court, and only if there is clear convincing evidence that:

a. The individual poses a direct threat to public health due to behavior, and the individual will not or cannot change.

b. Isolation is necessary to protect public health and is the least restrictive alternative.

VIII.6 The Educators Dilemma

Teaching about AIDS in schools and other settings presents a very real dilemma for educators. Unlike many other subjects such as math and social studies, there is little agreement on when to teach AIDS to school children or persons with developmental disabilities, what should be taught, and what is the best context in which to present the material. The problem is further complicated by the fact that many have difficulty determining where the most appropriate setting is for discussion of such intimate issues. Consequently, they encourage local agencies and school officials to avoid discussing AIDS. In other instances, agency personnel, teachers and school officials are often uncomfortable with the content material. In some states teachers must be aware that state law requires prior written parental consent before including any aspect of contraception in the curriculum.

As noted earlier in this discussion, the majority of the literature suggests that the goal of an effective HIV/AIDS education program should be not only to inform individuals of the imminent dangers of the virus, but also to integrate the information

into a much broader context of learning. That context should guide individuals toward avoidance of dangerous behaviors based on the best knowledge available about modes of transmission (sex, IV drug use). For the developmentally disabled population, the largest challenges to address in such education are: (1) the learning difficulties of this group, and (2) the necessity of the highest quality, most successful teaching strategies available given the life or death consequences for not providing adequate instruction.

VIII.7 Resources Addressing the Legal Issues

AIDS and persons with developmental disabilities: The legal perspective (1989). Rennert, S., Parry, J., & Horowitz, R. Washington, D.C.: American Bar Association.

HIV infection in children: some ethical conflicts (1989). Macklin, R. Technical Report on Developmental Disabilities and HIV Infection, 3, 4 pp.

Public Policy Affirmations affecting the planning and implementation of Developmental Services for Children and Adults with HIV Infection, (1989). Crocker, A.C., Cohen, H.J., Decker, C.L., Rudigier, A.F., Harvey, D.C., Silver Spring, MD: AAUAP/Administration on Developmental Disabilities Conference on Developmental Disabilities & HIV Infection, 13 pp. (Used by New Mexico, Alabama)

Issue paper: confidentiality vs. the need to know (1989). Breen, L.J. Sacramento, CA: Dept. of Developmental Services. 4 pp.

HIV infection legal issues: An introduction for developmental services (1989). Harvey, D.C. & Decker, C.L. In Technical Report on developmental disabilities and HIV infection. Silver Spring, MD: AAUAP. 6 pp.

Policy on social-sexual development: right to protection from exploitation, abuse and sexually transmitted diseases (1989). Sacramento, CA: Dept. of Developmental Services. 1 pp.

Policy statement on AIDS (1988). Albuquerque, NM: National Alliance for the Mentally Ill, 6 pp.

Confidentiality and AIDS (1987). New York, NY: Office of Mental Retardation and Developmental Disabilities, 2 pp.

Tennessee Department of Health and Environment AIDS Policies (1988). Nashville, TN: TDHE, 8 pp.

Risk Management, Quality Assurance, and Health Care Policy dilemmas (1989). American college of Utilization Review Physicians, 4 (2), pp. 45-55. Washington D.C.: Mental Retardation and Developmental Disabilities Administration.

IX. SUMMARY AND RECOMMENDATIONS

IX.1 Introduction

In this concluding discussion we find ourselves in something of a quandary. At the outset, the AIDS epidemic has not yet impacted upon Montana's developmentally disabled population at this point in time. The disease is therefore not perceived as an imminent threat calling for an urgent response to address it. There is the possibility that the lack of such urgency could lead to a degree of complacency, resulting in inaction until a crisis does develop.

The present status of the AIDS disease within our population of persons with developmental disabilities cannot be taken as an opportunity to avoid addressing the situation to any degree. Rather, Montana is exceedingly fortunate to be in a position to systematically engage in proactive pursuit of measures which could hopefully prevent this national problem from becoming a problem for our state.

As discussed in Section II.3 Risks to Persons with Developmental Disabilities, the sexuality risk factors to which especially those individuals residing in community group settings or semi-independent situations are exposed is potentially much higher than previously thought. This population is sexually active, limited in comprehension of the hazards of that activity, limited in self esteem and impulse control, and potentially prone to shared sexual partners and sexual abuse.

Within the general population, AIDS prevention and systematic policies and procedures for addressing prevention and management are viewed as critical, especially for those falling within high risk categories. It is only reasonable to

conclude our population of persons with developmental disabilities should receive the same degree of attention regarding their welfare. This contention is supported by the following points: (1) the high degree of vulnerability of this population, (2) the service system's basic obligation to protect and care for this relatively dependent group of individuals, (3) the advantage which can be gained by proactively addressing a disease which can only be effectively dealt with through prevention education and procedures.

To mount an effective campaign in prevention of the spread of HIV infection within the Montana developmentally disabled population a comprehensive, organized effort must be undertaken. To be effective, the endeavor must incorporate the collaborative involvement of the variety of Montana provider organizations and systems which are in place to serve Montana's developmentally disabled population. Such organizations include the Montana Developmental Disabilities Division, the Developmental Disabilities Planning and Advisory Council, Department of Family Services, Department of Institutions, residential provider agencies, work activity and day programs, Advocacy programs, Montana University Affiliated Rural Institute on Disability and other programs as identified.

The nature of this collaborative undertaking requires that planners possess an understanding of the complexities of the misunderstood but highly lethal medical condition associated with the HIV virus. This concerted effort must therefore draw upon support and expertise in the domain of HIV infection. Such support and knowledge available from the Department of Health and Environmental Sciences,

programs such as Planned Parenthood, and those within the medical community will serve as an integral component in this campaign.

Following are the major recommendations for action to prevent the spread of HIV infection within Montana's developmentally disabled population. To the left of each activity within the list of recommendations the suggested personnel are designated that would most appropriately assume primary responsibility for accomplishing that activity. Many of the activities identified for DD Division staff have already been implemented.

IX.2 Recommendations for Education and Training

As the literature on the subject indicates, there are no vaccines available to prevent contracting the virus, and at this time, no fail-safe medical treatments are available to halt the progression of the disease once an individual is infected. Consequently, prevention education and modification of certain behaviors serve as the key components in this endeavor. It is therefore the obligation of the HIV Prevention Project for the Developmentally Disabled (HIVPPDD) and the agencies participating therein to educate employees and clients about this disease. To be truly effective, it is imperative that the HIVPPDD and agencies assist licensed/funded community providers in fulfilling their own education and training responsibilities for both clients and staff. It should be understood that education is an ongoing process. All staff and clients must have current and relevant education and training. The

content must be tailored to meet the specific needs of the client, family or staff. The core objectives of an education program are:

1. To increase the knowledge base about HIV infection
2. To eliminate prejudice and fears at the work place and service sites.
3. To adopt procedures and encourage policies that will reduce the risk of infection to clients and staff.
4. To improve the delivery of services in this regard.

Expected outcomes when conducting education/training include increasing sensitivity, increasing the quality of services/work, and increasing the quality of life of individuals served. It is understood that monitoring and evaluation are an essential component in education/training efforts.

Identification Key:

HIVPPDD-S = HIV Prevention Project for the Developmentally Disabled - Staff

HIVPPDD-B = HIV Prevention Project for the Developmentally Disabled - Board

DDD = Developmental Disabilities Division

CSP = Community Service Providers

ATRDSP = Staff training project funded by DD Planning and Advisory Council

IX.3 Client Education Recommendations

HIVPPDD-B/S	a.	Identify the components for a client HIV/AIDS education program.
HIVPPDD-S	b.	Develop or adapt from existing materials a client HIV/AIDS education program specific to Montana's developmentally disabled population, appropriate to their age, level of understanding, and degree of risk behavior.
HIVPPDD-S	c.	Demonstrate the applicability and usefulness of the proposed education/prevention model component by pilot testing its use with high risk sexually active persons with developmental disabilities.
HIVPPDD-S	d.	Produce model materials with accompanying guidelines for dissemination of the model by community-based service providers and public school programs.

HIVPPDD-S/ DDD	e.	Disseminate HIV prevention education program through workshops at 4 sites in Montana, encouraging providers to establish educational programs appropriate to the needs of their clients utilizing models available for their use.
HIVPPDD-S/ DDD	f.	Provide technical assistance to providers in establishing and implementing client HIV educational programs.
HIVPPDD-S	g.	Access or develop specialized programs to educate persons identified as having certain high risk behaviors.
DDD/ HIVPPDD-S	h.	Evaluate implementation of activities a - g.

IX.4 Community Service Providers (CSP)

HIVPPDD-S/ DDD/CSP	a.	Assess the staff education needs in community-based provider agencies.
HIVPPDD-S/ DDD	b.	Make HIVPPDD and Division technical assistance regarding client/staff education programs including developed materials available to providers.
HIVPPDD-S/ ATRDSP	c.	Develop or adapt existing staff training programs to include instructional content and policies which can be used as models for providers.
HIVPPDD-S	d.	Provide staff training and awareness workshops at 4 sites in Montana (Missoula; Helena, Great Falls, Billings).
HIVPPDD-S/ DDD/CSP	e.	Encourage provider agency executives and board members, as part of their policy making responsibilities, to receive education concerning the disease, models by which policies can be developed, and content appropriate for decision making.
DDD/CSP	f.	Include HIV education in DD Division requirements for ongoing education and training conducted by providers. The content should include information about the definition of HIV virus, its clinical scope, transmission, prevention and identification of resources.
HIVPPDD-S	g.	Evaluate implementation of activities a - e.

IX.5 Employees Within State Agencies (DDD, OPI if applicable)

DDD a. Promote the identification and prevention of HIV transmission by providing all employees with a program of basic HIV/AIDS education.

DDD b. Specify the content of the education program to include information about HIV, encompassing its definition, clinical scope, transmission, and prevention, especially at the work place. Education should include a review of the Division policies and their application at the work site. Additional resource information should be provided.

DDD c. Include education about HIV infection in new employee's orientation.

HIVPPDD-S d. Develop or adapt specialized educational programs/training regarding HIV and persons with developmental disabilities for health care professionals such as physicians, nurses, psychologists, social workers, counselors and other direct care employees.

DDD e. Include people with HIV/AIDS or members of their support groups in the design and presentation of educational and training materials and program.

HIVPPDD-S f. Develop informational brochures for agency personnel and clients adapted specifically to Montana and the developmentally disabled population. The brochures should serve to:

1. Assist in identification of appropriate means for prevention of contracting the HIV virus.
2. Assist in identification of potentially existing HIV cases.
3. Inform clients, families and providers regarding their rights to services, methods of appeal if services are denied, and organizations which can assist with appeals.

DDD g. Identify individuals who will serve as resource persons within the Division and other agencies, able to conduct HIV/AIDS education and training for employees, clients and families.

DDD/ HHVPPDD-S h. Coordinate training activities within the agencies to ensure consistency and quality.

DDD/ HIVPPDD-S i. Evaluate implementation of activities a - h.

IX.6 Recommendations for Policy Development - Introduction

Policies and procedures must be developed, issued and implemented by the service system in place for persons with developmental disabilities. They are necessary to promptly and appropriately identify the presence of HIV infection, and ensure that persons with HIV infection are served in a timely, effective, and appropriate manner. They also serve the purpose of ensuring that services are coordinated and consistent. Special attention must be given to the paramount importance of individual rights and confidentiality.

Policies should be responsive to the needs of the individuals being served as well as the agencies providing services, their staff and other clients. As a result, policy development should occur through a partnership among the Developmental Disabilities Division, its regional offices, and the community-based providers. To ensure responsiveness, provisions should allow providers, subject to DDD approval, to modify certain policies and regulations so that they can provide services to persons with HIV in the most effective and efficient manner. Predefined service delivery principles adopted by the HIVPPDD should be the basis for approval.

Policies concerning HIV infection should take into account the specialized needs of particular client groups as well as the variety of services which are needed. Each community-based provider should develop its own policies appropriate to the needs of its clients and consistent with the policy guidelines issued by the DD Division. Providers should be responsible to assure policies are consistent with

Departmental policies, and the service delivery principles. The Division should ensure that such policies are developed.

IX.7 Recommendations Regarding Policy Development Guidelines

1. Define the scope, process and content of policies.

HIVPPDD-B HIVPPDD-S
a. Enlist the participation of a broad-based group, including those affected by policies and those with responsibility for implementation.

HIVPPDD-B
b. Define values which serve as the basis for policies and procedures.

HIVPPDD-B HIVPPDD-S
c. Write policies where appropriate to apply to all persons with infectious diseases as well as staff and other clients.

2. Promote and ensure consistency of policies.

HIVPPDD-B
a. Develop and implement policies in a timely manner.

HIVPPDD-S
b. Share policies with other agencies and providers.

DDD/ HIVPPDD-S
c. Establish the role of the DD Division's AIDS Coordinator and other appropriate groups in provision of technical assistance to community-based providers; and review policies for consistency, accuracy and appropriateness.

DDD
d. Develop an appeals process.

DDD/ HIVPPDD-S
e. Evaluate implementation of activities 1. a - c, 2. a - d.

IX.8 Strategies for Implementation by Community-based Providers

In order that policy and program development by the local developmental disability service providers is compatible and consistent, the following strategies are recommended:

1. The associations representing community based providers, where appropriate, and who are responsible for developmental disabilities services should review the principles adopted by the HIVPPDD, and the full report to make certain they are aware of the consensus direction regarding HIV policies.
2. Regional office DDD staff should review HIV policies already developed by their provider agencies for consistency with the HIVPPDD principles, and should request that providers develop policies where gaps exist.
3. Provider associations should make certain they have current information on the HIVPPDD principles and Departmental direction.

IX.9 Strategies for Implementation by the DD Division

It is recommended that the Division consider the following strategies to assure cross-program consistency in the development of program-specific policies on HIV infection:

1. The Division should be a prime information source about HIV infection for the community-based service agencies.

2. The Division should provide updated information and directives to community service providers on a regular and timely basis.
3. The Division should provide technical assistance to associations and providers in the development and implementation of HIV policies.
4. The Division should develop and revise regulations and bulletins regarding issues such as confidentiality, testing, non-discrimination, education and training in order to implement recommendations in this report.

IX.10 Discussion

Concerns arise regarding the limited memory retention, comprehension and generalization abilities of individuals with developmental disabilities the recommended instruction is to address. Those limitations, as discussed in the Introduction to the report, place this population at a relatively higher risk for contracting the virus. In like manner, the conditions markedly influence the abilities of these individuals to acquire the quantity of information and complexity of the prevention education necessary to be effective. Other factors such as impulse control and self esteem problems compound the challenges to be overcome in the prevention of spread of HIV virus in our state.

Implementation of the education prevention plans and development of policies and procedures will serve as critical steps in Montana's formulation of a united front with the goal of avoiding introduction of the HIV infection within the developmental disabilities community. HIV prevention, especially in the field of developmental disabilities is in infancy stages of development. Nevertheless, the materials available represent the most current instructional methods found in the area of education regarding sexuality. These qualities combined with the foremost methods for teaching

skills to persons with developmental disabilities enhance the possibility that the onset of the disease within this group in Montana will be delayed, or potentially even avoided if the recommendations discussed are effectively implemented.

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AIDS/HIV Curricula receiving favorable reviews by AAHE and CEC AIDS/HIV Education Project

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AIDS Instructional Guide - Grades K-12
New York State Education Department
The University of the State of New York
Bureau of Curriculum Development
Albany, NY 12234

AIDS Prevention through Education - Sample Curriculum
South Dakota Department of Education
700 Governors Drive
Pierre, SD 57501

Instruction About AIDS in Wisconsin Schools
Wisconsin Department of Public Instruction
1255 S. Webster Street
P.O. Box 7841
Madison, WI 53707

AIDS Supplemental Guide - Health Education
Hawaii Department of Education
Office of Instructional Services
General Education Branch
P.O. Box 2360
Honolulu, HI 96804

AIDS Education - Supplemental Teaching Guide
Columbus Health Department, AIDS Program
181 Washington Blvd.
Columbus, OH 43215

AIDS Instructional Curricula for Persons with Developmental Disabilities

Guide to Curriculum and Planning in Health Education, available through Bureau for Pupil Services publication sales dept. Received Guide supplement, Instruction About AIDS in Wisconsin Schools

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Responsible Healthy Lifestyles: Teacher Resource File for AIDS Education - levels 3 - 12 (1989). Moss, J.R., Griffin, B.T., Morgan, B.C., & Hess, S. Salt Lake City, UT: Utah State Office of Education, 90.

Safe DDATE: Developmental Disabilities/AIDS Training and Education (1988). Long Beach, CA: California State University, Department of social Work. Educational sessions targeting the HIV/AIDS related needs of dev. disabled persons. (copy not enclosed).

Universal Precautions/AIDS (1988). Des Moines, Iowa: Div. of Mental Health, Mental Retardation, and Dev. Disabilities, 7 pp.

Staff Training Materials

One Step Index System (1989). Boston, MA: DMR, 104 pp. AIDS training curriculum for employees of all DMR operated, licensed or funded programs. Includes AIDS education and information resources, and numerous literature pieces.

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II. Policy and Procedure Materials

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P.O. Box 6003
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