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INTEGRATION OF INDIVIDUALIZED MENTAL HEALTH SERVICES INTO THE SYSTEM OF CARE FOR CHILDREN AND ADOLESCENTS

John E. VanDenBerg, Ph.D.

ABSTRACT: Many states have developed "systems of care" which are organized networks of service alternatives for children with emotional disabilities. However, in some states, these systems did not have a positive effect on the most disabled of youth and their families. A viable option is "wrap-around" or "individualized" services which, when integrated into system of care services, can be more effective and less expensive.

Services to children and adolescents with emotional disabilities or with neurobiological disorders, and their families have evolved significantly in the last decade. Not long ago, this group had few options for services other than outpatient therapy or admission to a psychiatric hospital. In the late 1970s and early 1980s, a national movement to expand the amount and type of services delivered to these youth and their families began. This was in part prompted by several key court decisions. The most notable was Willie M. v. Hunt, which resulted in expanded services in North Carolina to children and adolescents with serious emotional disabilities who were also assaultive (Behar, 1986). In addition, the publication of *Unclaimed Children* (Knitzer, 1982) was a benchmark in the effort to develop service alternatives. Knitzer argued that the absence of appropriate services was a national disgrace that left over two million seriously emotionally disturbed children unserved in the United States each year.

As a result of the Child and Adolescent Service System Program (CASSP) of the National Institute of Mental Health (NIMH), many states received funds

John VanDenBerg is Director, Center for Research and Public Policy, Pressley Ridge Center, 530 Marshall Ave., Pittsburgh, PA 15214.

to begin restructuring state mental health departments to include a focus on children and adolescents with emotional disabilities. The CASSP grants eventually reached all states and have had a national impact on how services are planned and implemented.

An important development that was initiated through CASSP was the concept of "a system of care" for children and adolescents with emotional disabilities. In the book, *A System of Care for Severely Emotionally Disturbed Children and Youth,* which has been widely used by Alaska and other states as a model for development of services to youth, Stroul and Friedman (1986), describe a "system of care" as follows:

> A system of care is a comprehensive spectrum of mental health and other necessary services which are organized into a coordinated network to meet the multiple and changing needs of severely emotionally disturbed children and adolescents (p.iv).

States that established system of care alternatives to the standard outpatient and inpatient services focused on the development of case management, respite services, day treatment, therapeutic foster care, and other categorical services. In some states, however, even these improvements in the availability of service alternatives did not address the needs of the most disturbed of the youth who were institutionalized on a long term basis (Zeigler-Dendy, 1989). Alaska was one CASSP state in this situation and it successfully sought solutions through the development of "wrap-around" or "individualized" services.

THE ALASKA YOUTH INITIATIVE

In 1985, senior staff in the Alaska State Departments of Education (DOE) and Health and Social Services (DHSS) realized that both departments were sending increasing numbers of emotionally disturbed youth to receive services outside of Alaska. The practice was a problem for a variety of reasons including excessive cost, questionable treatment results, and legal and ethical concerns.

Alaska was only one of many states that regularly sent their most troubled youth outside of state to receive services. In the past, Alaska had up to 200 youth in out-of-state care at one time. This number was reduced to approximately 90 when in-state residential facilities were developed during the late 1970s. In the early 1980s, the number of youth in out-of-state care fluctuated between 40 and 90, depending on the available budgets of DOE and DHSS. Alaska's population is approximately 525,000 including approximately 176,000 residents under age 19. At times, during difficult budget cycles, youth were brought back from out-of-state placements and returned to their communities without additional services. Other youth who turned 18 years old in out-of-state care were returned to Alaska.

In 1985, an inter-departmental committee was formed to address growing

pressure from school personnel, child welfare workers, and juvenile justice officials to send even more youth out of state. This committee, the Interdepartmental Team (IDT), was composed of senior staff from the state-level offices of the DOE, the DHSS Division of Family and Youth Services (DFYS), and the DHSS Division of Mental Health and Developmental Disabilities (DMHDD). As a result of this committee's work, the Alaska Youth Initiative (AYI) was formed in 1986.

In the traditional "categorical" model of service delivery, children are brought into pre-existing programs. When a child's needs are not met, he or she is often referred elsewhere or may be inadequately served. In contrast, an individualized or wrap-around intervention is developed and/or approved by an inter-disciplinary services team, is community-based and unconditional, is centered on the strengths of the child and family and includes the delivery of coordinated, highly individualized services in three or more life domains of a child and family. An inter-disciplinary services team, at a minimum, includes: 1) the parent and/or surrogate parent i.e., foster parent or guardian; 2) an appropriate representative of the state, if the child is in its custody, e.g., social worker or probation officer; 3) a lead teacher and/or vocational counselor; 4) a therapist or counselor, if the child is in mental health treatment or should be in mental health treatment; 5) a case manager or services coordinator, i.e. a person who is responsible for ensuring that the services are coordinated and accounted for; 6) an advocate of the child and/or parent; and 7) other persons who are influential in the child's or parent's life and who may help develop effective services—such as a neighbor, a physician, a relative, or a friend. In addition, the child should be included on the team unless it would be detrimental in some way.

Individualized services are based on the specific needs of the child and family, and are not tied to a particular categorical intervention model. "Needs" are defined in positive terms, such as a child's need to express him or herself in an art form or the need to continue to excel in school. The need may be for remedial action, such as a parent's need to find employment or a child's need to stop hurting other children by learning appropriate interaction skills. The individualized services may include both traditional forms of intervention, like therapy and foster care, and non-traditional approaches, such as hiring a special friend, bringing in staff to live at the family home, and special recreational services. In the individualized model, traditional services should be used only when they can be tailored to the specific needs of the child and family.

Life domain needs are those areas of basic human need that everyone experiences. These are: 1) residential, i.e., a place to live; 2) family or surrogate family; 3) social relationships; 4) educational and/or vocational; 5) medical care; 6) psychological/emotional support; 7) legal assistance, especially for children with needs in the juvenile justice system; 8) safety, i.e., the need to

be safe; and other case-specific life domain areas, such as cultural/ethnic needs or community involvement needs.

In an individualized model of services, an interdisciplinary team of persons (including the parent) first asks the question "What does this youth need so that he or she can get better?" The team looks at not only medical issues, but at family, friends, vocational, educational, psychological, safety, economic, and other areas of need. The team agrees that they will offer the youth unconditional care. This means that if the youth's needs are not met, the individualized program will be changed, and the youth cannot be "kicked out" when he or she exhibits the very disabilities which stimulated entry into the services in the first place.

The individualized model has been replicated and refined throughout the United States during the past several years. Individualized service programs like AYI are typically partnerships between a state and private agencies.

SIGNIFICANT PROGRAM OUTCOMES OF AYI

The Alaska Youth Initiative has had two principle goals since 1986:

1. To limit further inappropriate institutional and out-of-state placements. This goal has been met and the flow of youth going to out-of-state placements has been stopped. Only two AYI youth, out of over 117 originally placed out-of-state, or diverted from being sent out, have had to be sent out-of-state, and both of these were in the first two years of AYI. These youth later returned to AYI.
2. To transition back to Alaska youth who had been placed out-of-state. This goal has resulted in only one youth still in placement outside of Alaska. No youth who was returned to Alaska through AYI has been placed out-of-state again.

PRINCIPAL CHARACTERISTICS OF INDIVIDUALIZED SERVICES

Sewell (1990), a AYI staff member, has identified 10 features of individualized services for children and adolescents with emotional disabilities. Individualized services function by:

1. Building and maintaining normal lifestyles
2. Insuring that services are client-centered
3. Providing unconditional care
4. Planning for the long-term
5. Working toward less restrictive environments
6. Having competent, trained providers of service

7. Establishing consensus among key decision makers in the child's treatment
8. Funding services with flexible budgets
9. Installing a "gatekeeper" function
10. Developing measurable accountability

Although AYI is still evolving, after the first five years, the program has been recognized nationally and internationally as a model for serving youth who have severe emotional disturbance. In the *Care of the Seriously Mentally Ill: A Rating of State Programs,* Torrey, Erdman, Wolfe, and Flynn (1990) promoted AYI as a promising development:

> Services to seriously emotionally disturbed children in Alaska have been closely watched by child mental health advocates nationwide. The reason is that for the past few years, the state's Department of Health and Human Services and the Department of Education have been operating the Alaska Youth Initiative (AYI), an ambitious program to bring home the numerous children sent out of state due to a lack of services in Alaska. AYI emphasizes flexible services that are tailored to the needs of each child; the program's funds can be used to purchase virtually any service that a child needs to remain stable and at home (p. 74).

Burchard and Clarke (1990) state: "The most impressive demonstration of the [individualized] approach is the Alaska Youth Initiative (AYI), where, after two years of individualized care, almost all of the children who were in residential treatment programs out of state are now in less restrictive programs in Alaska" (p. 50).

EXAMPLES OF AYI SUCCESSES

Keith, age 10, was abandoned by his parents at age 2, and had failed in 13 foster homes. He attacked his teachers at school on numerous occasions and once physically destroyed a classroom. He was referred to a locked psychiatric hospital in Oregon but was diverted into AYI instead. During the first six months of his program, Keith showed many challenging and disturbed behaviors. Now, because of the success of an intensive individualized plan which included creative respite services, participation in a non-deviant peer group, and an anger management program, Keith has lived with the same highly trained, specialized foster parent for two years and adoption is being considered. He is doing well in school, is happy, and has great potential. Keith had a determined treatment team which did not give up on him. The cost of his care has been 37% of the cost of out-of-state placement.

Suzy, age 18, has been transitioned out of AYI for the past six months. She came into state custody at age 4 because of abuse by her parents. After failing in school as a special education student, she came into AYI at age 15 with a long history of assault, suicide attempts, running away, and drug use. She had failed in all placements with family members and foster parents, and frequently falsely accused caregivers of sexual abuse. The local AYI staff, together with the school, mental health center, and DFYS staff, formed an interagency team to design and jointly implement a specialized "shared-care" arrangement. Shared-care consisted of three shifts of staff who focused on teaching Suzy

alternative behaviors; the prospective foster parents served as part of the staff. This approach, using community-based services, prepared her to live in specialized foster care. She is now in school full-time, has been drug-free for over two years, is living with a caring family member, and is planning to enter college after she graduates from high school.

Gerald, age 18, came into AYI at age 16 after spending three years in a locked psychiatric hospital in Texas, at a total cost to the Department of Education of over $300,000. He was from a small village without any formal services available. Shortly after returning from out-of-state care, he assaulted a neighbor and stole from the local church. Through itinerant AYI staff, monitoring from local staff, and a highly individualized plan which included an interdisciplinary team to plan and coordinate services, a work program, and intensive family support, he has recently graduated from high school, is working part-time as a laborer, and is a contributing member of his village.

DISADVANTAGES OF INDIVIDUALIZED AND CATEGORICAL MODELS OF SERVICES

Although AYI has been successful for a wide range of youth, several problems exist with a "pure" model of individualized services, where each facet of the service is specially created for a particular client. In addition, problems also exist with categorical programs, where each client receives the same service.

Disadvantages of Individualized Services

The most important disadvantage of individualized services is fewer clients can be served compared to a categorical service system. Categorically designed group intervention programs, such as group therapy or day treatment, typically serve many individuals at one time. Therefore, individualized services can cost more than categorical services.

Another disadvantage is that many service providers are not familiar with the approach. A major source of resistance in Alaska has been individual therapists and categorical program staff who have learned technically sophisticated interventions which are based on a particular theory or program model. These staff have been trained that to follow a predetermined set of procedures results in client success. Clients who do not improve after the intervention are often labeled as resistant. In an individualized system of services, when a client fails to improve, the helping professional must modify or abandon predetermined program models. This change is especially challenging for many mental health professionals, and in the experience of the author, many will not alter their approaches, even when faced with their failure. If these professionals are influential in the community, they are often capable of organizing a great deal of resistance to the establishment of individualized service models.

Another shortcoming of individualized services is their reliance on inter-agency involvement. For example, a mental health center can administer a traditional individual therapy service without conferring with teachers at the local school or working with social service agencies. However, in an individual, needs-based approach, it is impossible to overlook needs that cut across other agencies. Inter-agency involvement is necessarily more expensive in terms of

staff time. Finally, with individualized services, the budgeting procedures of flexible funding can be cumbersome and even prohibitive. Administratively, it is much easier to provide grant funds for a residential program than it is to individually plan for each youth.

Disadvantages of Categorical Services

Although categorical services may be more cost effective, familiar to providers, use less administrative staff time, and be effective with some clients, many disadvantages exist, especially for emotionally disturbed youth or youth with neurobiological disorders. First, and most critical, is the effectiveness of categorically-based interventions. In AYI, almost all youth were provided with categorical services as they failed in placement after placement. Not until the youth received services from AYI did the cycle of failures stop. AYI staff have learned that the more individualized the service, the more effective it is. And, the more disturbed the youth, the more individualized the service must be. The effectiveness of treatment is in fact critical. Martin (1984) indicated "the only constitutionally acceptable purpose for state intervention into the lives of handicapped persons is to provide a quid pro quo of effective treatment" (p. 97). Because of a lack of effectiveness, categorical services have failed the youth who come into AYI.

Categorical services may be difficult to build in rural areas. Small towns that cannot support an entire day treatment program can develop an individualized program around a child as an alternative. In Alaska, children and adolescents with emotional disabilities or neurobiological disorders have been individually served in tiny Eskimo villages, hundreds of miles from the nearest mental health provider.

Categorical programs may violate the right of a youth to have an individualized approach to treatment. Court cases such as Wuori v. Zitnay (1978) have clearly established the right for a disabled person to receive treatment based on the individual's special needs. VanBiervliet and Sheldon-Wildgen (1981) note that "It is clear that treatment plans should be individualized, tailored to a particular person's needs and abilities" (p. 112).

Another common problem with categorical services is the high rate of staff turnover, especially in rural states. In Alaska, the average turnover rate exceeds 25% per year. However, the turnover rate in AYI is less than 5%. Interviews with AYI staff indicate that they are highly motivated by seeing positive outcomes with youth who normally are not adequately treated. As a result, these staff remain challenged in their positions.

MODIFYING CATEGORICAL SERVICES THROUGH THE INDIVIDUALIZED MODEL

The disadvantages of the individualized and categorical models of service can be ameliorated by combining their advantages. After the initial success in AYI, questions arose about the applicability of the individualized care model to

other programs for youth with less severe emotional disabilities and to programs for persons with other disabilities. For example, in 1986, Alaska began to develop several model systems of care. Although these new programs were valuable for some less disturbed youth and their families, the programs were not able to serve youth with more severe problems. One reason was because they were designed as categorical interventions. If a youth's needs did not fit the program model, the youth was referred to other (often non-existent) programs. This phenomenon was, in part, a function of the categorical program design. For example, the program often did not individually assess needs and had no flexible funding. As a result, the programs could not commit to "unconditional care," which meant that if a problem occurred, the program would change rather than reject the youth from services.

The Alaska DMHDD has since modified several of these programs. The first trial of this effort was a program in Fairbanks which offered a range of services including an intensive diagnosis and evaluation, home-based services, case-management, therapeutic foster care, and a small group home for children ages 10–13 who needed to be in out-of-home care. This was joined by a day treatment program that was managed by another agency. Although counselors and management were enthusiastic, staff were often resistant to providing services outside those routinely offered to youth. Working collaboratively with the staff, the DMHDD awarded an individualized intervention grant ($25,000 the first year) that could be used to supplement program funds. The flexible funds had several rules. First, the funds could not be used to hire new staff, equipment, or supplies for the overall program. The program could not pay parents to care for their own children. When the fund was used, an audit trail required multiple signatures and receipts for all purchases.

The initial results from these funding modifications, now applied to other programs in the state, have been encouraging. The Fairbanks region now has the lowest rate of referral in the state to inpatient hospitalization at the Alaska Psychiatric Institute and no youth have been rejected from any of the programs.

Other Examples of Combining Services

The following case illustrates the creative use of need-based, individualized planning and the use of an individualized intervention fund managed by a modified categorical program:

> A youth in a day treatment program in a small city had been making slow but steady progress in controlling her behavior and catching up academically. The program had staff who worked with the family after school and on weekends. For the first time in many years, the family and the youth were stable and making progress. However, the single parent abandoned the three children during a crisis. In typical circumstances, the children would have been placed in foster care. However, the staff at the day treatment program felt that the disruption of the home environment would cause a major reversal of the gains already made by the youth. The staff of the day program made an agreement with the local child welfare office to use individualized intervention dollars to hire a substitute

parent to come into the home and care for the children until the crisis could be resolved. The staff trained this substitute parent to address the needs of the family and began working with the parent to help her return to the home. After additional respite care was obtained, the parent did return. The family soon stabilized and has maintained improvements for almost one year.

In this example, a relatively small amount of money (less than $2,000) was allocated to provide a highly individualized intervention which may have prevented the disintegration of a family. The approach allowed a staff to provide unconditional care, or "treat and educate no matter what it takes."

INDIVIDUALIZED INTERVENTIONS FOR PERSONS WITH DEVELOPMENTAL DISABILITIES

The state of Alaska had a sophisticated array of services for adults and children who have developmental disabilities. However, the services were largely categorically-based and frequently failed with persons who had complex needs. As a result, there were many youth and adults who were not being appropriately served. In part, based on the success of AYI, the legislature appropriated over $900,000 to develop individualized services for this group. These funds are allocated by regional coordinators who work with the component-based programs to develop individualized services. In one instance, $150,000 designated to a new group home for five developmentally disabled youth was diverted into individualized plans which were designed to keep each youth at home. In this instance, 10 youth were served with the same funds that would have served only five youth in more restrictive care. The individualized model has been applied now to all adults and children who have developmental disabilities in Alaska. Clients have their own designated funds which follow them: a practical example of "dollars following the client."

INDIVIDUALIZED INTERVENTIONS FOR ADULTS WHO HAVE A MAJOR MENTAL ILLNESS

In part, because of incentives provided by the Community Support Program of the NIMH and the advocacy efforts of the Alaska Alliance for the Mentally Ill, Alaska has a highly developed system of care for adults who suffer from a major mental illness. Like the original programs developed for persons with developmental disabilities, adult services are categorically-based and work well for clients whose needs match the program model, but are not as effective for clients with different needs. For example, all community-based group homes for adults will accept clients who have a diagnosed mental illness. However, if a client has an episode of violence, most programs will not accept the client, who may end up in more restrictive care or even become homeless and without services. If modified for individualized care, program staff would view the client's violent behavior as a need that requires specialized programming. For

example, if the violent behavior had visible antecedents, extra staff or an added activity could surround the client during high risk times, thereby preventing injury to the client or others.

The DMHDD has now begun to convert adult programs into modified individualized models. New funds were requested from the legislature to provide incentives for programs to adopt new techniques of individualized treatment. After these flexible funds were made available, initially to clients discharged from institutions, local agencies began to develop more individualized alternatives for clients.

NATIONAL TRENDS IN INDIVIDUALIZED SERVICES

A number of states are now adopting variations of the AYI individualized services model, specifically as a way to bring home their youth placed out-of-state. These states include Wyoming, Vermont, West Virginia, Washington, Montana, and Maryland. The State of Washington has successfully used a modified individualized services approach in a number of its counties. In these projects, teams of local agencies can apply for state funds to hire a case coordinator for their community. In addition, the agencies are given access to flexible funds. Working as a team, the agencies nominate youth whom they feel are at risk of being removed from the community. The case coordinators construct individualized plans, which are based on the child's needs, to access the flexible funds. All participants in the youth's services make unconditional care agreements. The initial results of these programs have been promising.

SUMMARY

In Alaska, the development of individualized services has benefited children and adolescents with emotional disabilities or neurobiological disorders and their families. The AYI program has successfully demonstrated that even the most disturbed youth can be served in the community. This finding challenges the standard practice in the United States of institutionalizing the most seriously disturbed youth, and furthermore promotes a new level of less restrictive, therapeutic alternatives. The AYI has demonstrated that traditional categorical services can become more effective with difficult clients if more individualized service alternatives are created.

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