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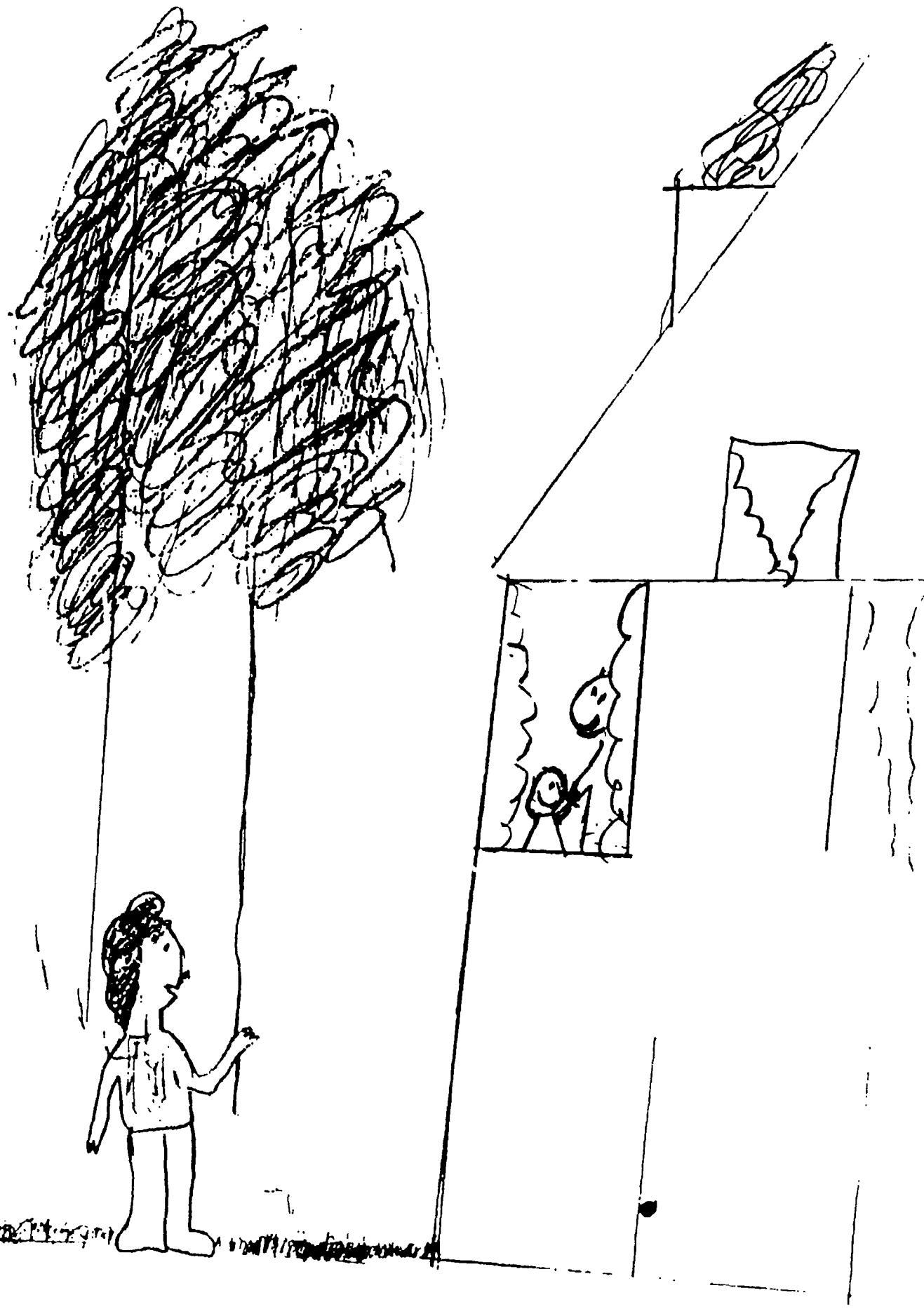
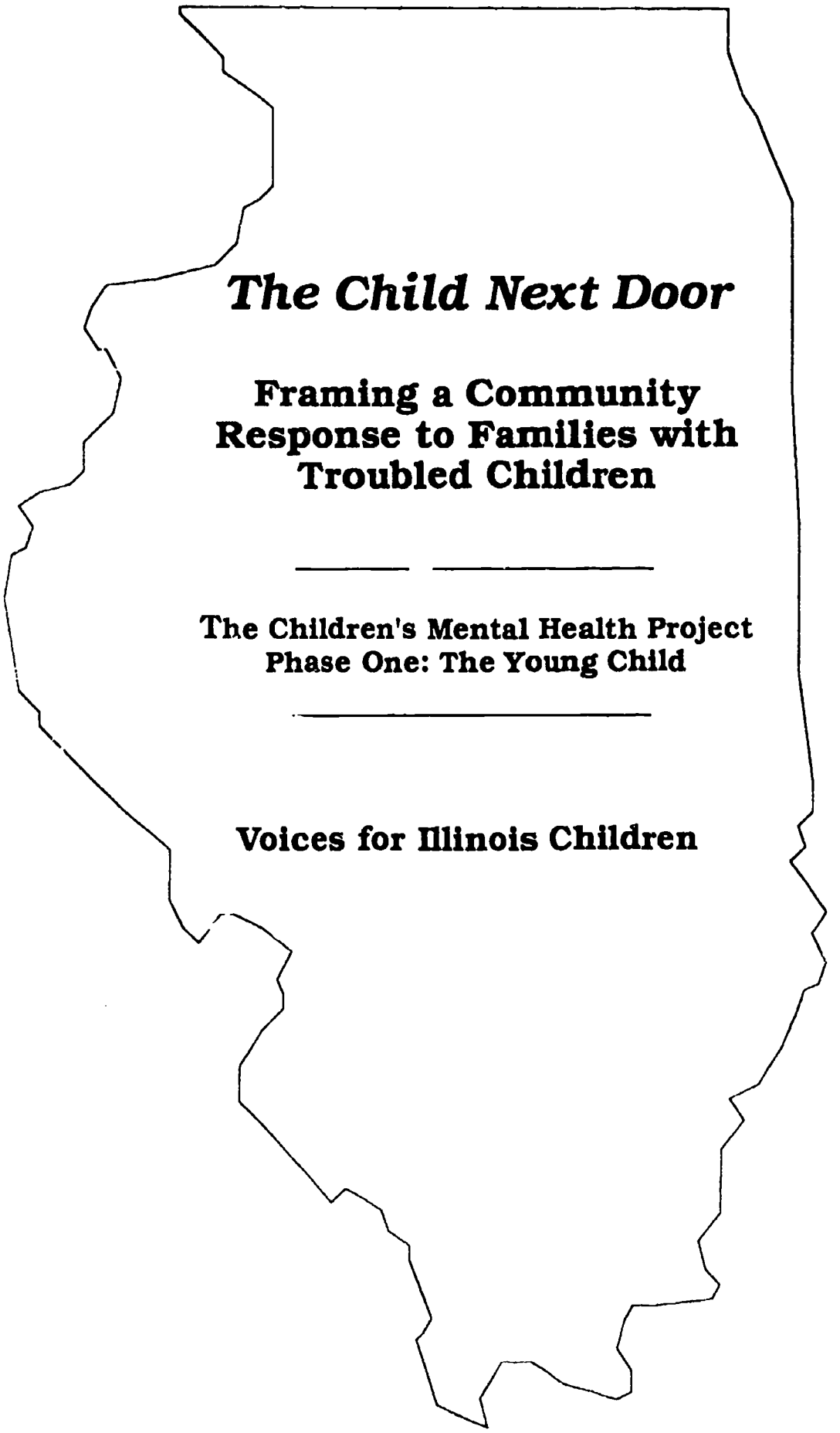
ABSTRACT

This report covers the first phase of the Illinois Children's Mental Health Project and establishes principles for helping children with emotional disturbances and their families based upon their actual needs. Section I examines the problem with a discussion of identification of those children at greatest risk, the role of the mental health system, and identification of needs. Section II looks at opportunities for helping these families in the areas of: medical/health care; child care; child welfare services; community-based, family support drop-in centers; community mental health centers; Head Start and children at risk preschool programs; preschool special education; provisions of Public Law 99-457; Medicaid funding for the Early and Periodic Screening, Diagnosis, and Treatment program; and advocacy. Eleven recommendations are made, including: increase efforts to identify young children and families in trouble; increase training of child care providers; establish community-based family support and drop-in programs; provide an array of children's services by community mental health centers; involve parents in planning early childhood special education services; plan for emotional and social development in early intervention efforts; and utilize Medicaid revisions to provide coverage for a broader range of community mental health services. Includes 25 references. (DB)

The Child Next Door

Framing a Community Response to Families with Troubled Children





The Child Next Door

Framing a Community Response to Families with Troubled Children

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The Children's Mental Health Project
Phase One: The Young Child

Voices for Illinois Children

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VOICES FOR ILLINOIS CHILDREN

Dear Reader:

One in eight children and adolescents in Illinois suffer from significant mental health problems. These problems affect how children participate in their families, how well they do in school, and how they make friends and take part in their communities. But too often these difficulties are not taken seriously, and the children drift year after year until they reach a crisis before they ever have a mental health intervention.

These problems can be attributed to organic causes, related to living conditions, life experiences, family functioning, or complex combinations of these elements.

There is growing knowledge about the importance of intervention early in the lives of some children. This report on young children, from birth to age five, underscores the critical importance of the first few years of life in forming the foundation for every child's future.

Our goal is to describe how troubled children and their families can be helped in their own communities. Some sources of help are not currently part of the mental health system, but can be important resources for families. We describe the importance of collaborative efforts between mental health professionals and the other people and programs families might be most likely to use.

The report includes specific steps that can be taken to improve mental health resources for young children in Illinois. During the next phase of the Children's Mental Health Project, VIC will work to implement these steps and develop policy options for school age children.

We encourage your response and your participation as we go forward.

Richard Mandel
Chair of the Board of Directors

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EXECUTIVE SUMMARY

THE PROBLEM

The mental health service system in Illinois is focused on children in crisis. The Department of Mental Health and Developmental Disabilities (DMH/DD) considers its target population the most severely emotionally disturbed children who are at immediate risk of extrusion from their family, school and/or community. While the Department's rhetoric emphasizes the provision of a "community-based continuum of services" from prevention to residential treatment, the reality is quite different. The focus is not on the possibilities of prevention and early intervention efforts, but on the challenges of meeting the needs of those who have already developed severe emotional disturbances. In effect, there is no comprehensive mental health system in Illinois.

Those families who do seek help may find themselves ignored, shuffled from one agency or service system to another, or identified as the source of the problems their children are having rather than potential partners in finding ways to help their children develop.

The problem in children's mental health is that children are getting too little too late. Many children do not receive any mental health services until they are in crisis or until they have "careers" which involve the special education, foster care, or juvenile justice systems. In the end, far too many children end up in these systems without receiving prior mental health interventions.

Some children whose development will be threatened by mental health problems show signs of behavior or psychosocial development outside the normal range at an early age. But far too often, because they do not fit into diagnostic, service or funding categories, these children receive no help until they get into trouble in elementary school. Earlier intervention is critical if the child is going to start school with a chance to succeed.

There are many possible ways to help children and families experiencing difficulties. Many are not currently part of the mental health system. This report establishes principles for helping children and their families based upon their actual needs. This report is the first phase of our Children's Mental Health Project. We have focused upon young children zero to five because children's mental health begins at birth and the first few years of life are critical in forming the foundation for the child's future.

WINDOWS OF OPPORTUNITY

In the last ten years there has been a significant expansion of knowledge about the development of young children. There is a greater understanding of how children from birth on integrate their cognitive, physical, emotional, and social experiences, and what impact families and environments have upon that development. There is also growing understanding about programs and interventions that can help children and their families. We must look for a variety of opportunities to enable families to get the useful help they need early in the life of their child.

Just as troubled children need the support of their families, these families need the support of others beyond the immediate family. Support may come from relatives, friends or neighbors; but for many it must come from organized resources in the community. In some communities there are insufficient resources to help these families.

This report considers ways to build on current resources and institutions, for example, health visitors, day care providers, Head Start and preschool programs, drop-in centers, and community mental health services, to respond to the needs of these children and their families. Such programs, with some extra resources and changes in their strategies, could provide considerable help to these families:

1. The medical and health communities must make further efforts to identify those children and families in trouble and connect them with appropriate resources. We need more trained home visitors who can assess a young child's developmental progress and teach parenting skills.

2. More child care providers should be trained in child development and have contact with mental health consultants. Under these circumstances they could respond more adequately to troubled children.

3. Every child needs an ongoing attachment to a parent or caregiver. Children who experience no such attachment or who have this primary relationship severed by placement in the foster care system are at special risk. Yet, many of these children never have a developmental or mental health evaluation or any mental health intervention. The Department of Children and Family Services must provide for the developmental needs of children in its care, including, where appropriate, additional educational and therapeutic programs.

4. Community-based family support and drop-in programs can provide a non-threatening place for parents to bring their children and to interact with others who may share a common culture. Parents can receive informal help, learn more about child development, and receive guidance about other community resources.

5. Community mental health centers need to provide an array of children's services which include prevention and early intervention.

6. Head Start and preschool programs play a critical role in building a positive alliance between children, parents and teachers which prepares a child for school. Head Start has standards for parental involvement and for a mental health component in their programs and these should be fully implemented. State-funded preschool, the Children at Risk program, should adopt similar standards.

7. School districts must identify all those children who are eligible for early childhood special education services. Parent involvement is crucial in the planning, decision making, and implementation of the Individual Education Plan (IEP) for their child. This process should build on the strengths of the child and family, as well as address the child's disability.

8. Early intervention services to be implemented under Public Law 99-457 must include in the definition of eligible children those who are at risk of substantial developmental delay. These early intervention efforts must be concerned with emotional and social development, and the mental health community must become active participants in this effort.

9. Illinois must take full advantage of the 1990 revisions in Medicaid which now provide coverage for a broader range of community mental health services.

10. Child and mental health advocates must work to build resources which focus first on what helps children and their families in their own homes and communities. Advocates must work to promote prevention and early intervention in children's mental health, along with comprehensive services for those children who have severe disabilities.

11. The Department of Mental Health and Developmental Disabilities must have a designated responsibility for promoting prevention and early intervention services focused on young children's mental health. The primary goal of this effort should be to reduce the incidence, prevalence and severity of emotional disabilities in children.

The challenges involved in raising mentally healthy children extend beyond the mental health system. This report identifies ways to make current programs more responsive to families with troubled children.

INTRODUCTION

The Children's Mental Health Project is concerned with very young children whose full development is threatened in a way that affects their social relationships and their emotional well-being. The causes of the problem may range from exposure to drugs while they were still in utero, to a dangerous poverty stricken environment, or to unknown factors. For some children the results are quite threatening: they may be very difficult to care for because the circumstances of their birth affects the parent-child relationship in a way that threatens their development even more; they may have difficulty playing with other children; and once they reach school age they may gravitate towards special education and behavior-disordered classrooms.

But there is substantial evidence that many of these children can be helped to diminish the ill effects of their condition and they might even overcome them completely. This project explores the ways in which families whose children are troubled can learn how to cope with the difficulties of raising them and can learn to maximize their children's development. The report looks at why the current mental health system is unlikely to be useful to many of these families and suggests a variety of alternative ways families with troubled children can be helped. In particular we ask:

1. Can we identify high-risk groups of children who are in danger of getting into serious social and emotional difficulties as they get older?

2. How do families support or thwart the healthy growth of a child?

3. What are the signs that a mental health problem is present?

4. Can families be helped very early in the life of a child?

5. Can we help high-risk children without stigmatizing them with labels?

6. How can a community help parents help their children?

The components of mental health may be characterized in a number of ways. A measure of mental health may be found through a comparison of a child's development and the milestones that are considered to be normal for that age and phase. Another measure may be found in the capacity of the caregiver(s) to provide for the basic needs of the child, while still another measure may be found in the opportunities made available for the child to realize his or her potential.

THE PROBLEM

- PRINCIPLES FOR HELPING CHILDREN AND THEIR FAMILIES
- WHO ARE THE CHILDREN AT GREATEST RISK?
- WHAT CAN HAPPEN TO CHILDREN WHO NEED HELP?
- WHY THE MENTAL HEALTH SYSTEM DOES NOT HELP THESE FAMILIES
- WHAT DO CHILDREN AND THEIR FAMILIES NEED?

THE PROBLEM

PRINCIPLES FOR HELPING CHILDREN AND THEIR FAMILIES

Any set of principles for young children's mental health should emphasize prevention, early intervention, and family support. The principles should stress reducing the practical difficulties families currently face, obtaining an assessment of their children's condition, and receiving local and non-labeling help. In the vast majority of cases, children between the ages of 0 and 5 whose behavior is outside the normal range do not easily fit into diagnostic categories. In particular, a child should not have to be labeled severely emotionally disturbed or mentally ill in order to receive help.

The following should be part of the guiding principles for promoting children's mental health:

- Mental health is an integral part of healthy development; healthy development includes cognitive, physical, emotional, and social development.
- Mental health begins at birth. The conditions of the mother's pregnancy, prenatal care, delivery, and post-natal care have an impact on the future mental health of the child.
- The goal of mental health policy and practice is to promote and, to the extent possible, assure that children realize their own potential.
- The needs of the family and the needs of the child are not always the same. Strategies should be developed for deciding priorities when both a child and a parent are troubled; the child has to be the higher priority.
- Relatives, friends and neighbors who might lend support and help can be a primary intervention resource and attempts must be made to identify who they are and what they can do.

- Local communities have an integral and important role in shaping and providing services.

- Poverty, homelessness, violence, and substance abuse pose fundamental risks to children's survival. In addition, they are such critical elements impacting on children's mental health that reducing the number of children who live in these conditions is imperative. Children living in any of these conditions should have prevention and early intervention services available which directly address these conditions.

- Severity of disability alone should not be the only criterion for intervention. Rather, the opportunity to have a beneficial impact should be a key criterion.

- Services and programs should involve parents and community participation to promote self-determination, raise self-esteem and strengthen the social fabric of the community.

WHO ARE THE CHILDREN AT GREATEST RISK?

Mental health problems in children involve emotions, behavior, and children's organic make-up. Some children are born with serious physical or mental impairments or develop them very early in life. The most severe psychiatric disorders in very young children affect cognitive skills, language development, behavior, and psychosocial development - virtually all aspects of the child's life. These children and their families are at great risk if they do not receive adequate support to help them manage.

Some children exhibit symptoms or behavior that indicate they are developing outside the wide range of "normal" physical, emotional, cognitive, and social development. For example, there is a three year old who does not sleep through the night, is aggressive in her play resulting in other children being hurt or afraid, and who is a continuing disruption in her day care center. Or, there may be a two-year-old boy who is listless, finds little or no pleasure in exploring and play, and is most often overlooked by any adults, including his parents, because it is as if he isn't even present. Or there is a preschool child who races around the special education classroom, throwing himself hard against the wall. Or, this child can be the abused or neglected child who is placed in foster care and very early in life knows the fear of being taken away from the only parents he or she has ever known.

Several factors put infants and children at risk. The circumstances surrounding the birth of a child can present risk factors. Perinatal complications, low birth weight, and premature deliveries can result in future mental health problems. Babies born with Fetal Alcohol Syndrome or born already having been exposed to drugs may develop mental health problems. Teenage mothers present a group of parents whose own developmental needs, inexperience, and economic instability constitute very real risk factors for their children and for themselves. There is evidence that children being raised in families with a prior history of mental illness or severe disorders may be at greater risk. Families with a history of drug or alcohol abuse also present a primary risk factor.

Abused and neglected children are at considerable risk of developing significant dysfunction or developmental delays. Depression, poor interpersonal development, and inappropriate aggression are examples of such behaviors. The youngest children in our society are often the most vulnerable and at greatest risk. In Illinois, according to "The State of the Child: 1985" children under three represented close to 25% of all reported abuse and neglect incidents; this is the highest for any age group. The highest rate per 1,000 children (27.4) was reported for this age group and 75% of the reported cases of abuse and neglect resulting in death are in this age group. We can estimate, based on 1984 figures, that in 1989 more than 10,000 children under three were found to be abused or neglected.[1]

Underlying many issues relating to children's mental health is the significant impact poverty can have on the development of children. Poverty is a serious risk factor in the mental and emotional development of children. For a low-income mother with young children meeting basic survival needs is very difficult. The stress of providing food, clothing, and shelter can significantly limit a mother's capacity to stimulate and play with her baby or young child.

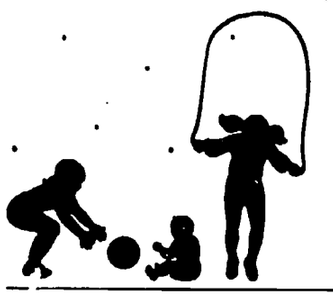
Mothers who live in poverty may have very little self-esteem and the harshness of life causes both parents and children to appear beaten down. People working with children who live in poverty describe babies and young children who are not clean or fed, who will not make eye contact with another person, who never smile, and who have nothing in their environments that would stimulate them. Or they speak about toddlers who will inappropriately hug a kindly stranger and scream when that person leaves. As one program director poignantly stated, "the face of a child reflects what is going on in the home."

In some homes or environments, the threat and/or incidence of violence is part of daily life. The presence of chronic danger requires children to make developmental adjustments. James Garbarino of the Erikson Institute equates this experience to growing up in a war zone. In recent testimony he stated: "That they survive at all is testimony to their resilience and to the efforts of the adults who care for them - parents, teachers, relatives friends, and therapists. These adults help the children of war hold on to a small piece of childhood, and a child with no childhood at all is a child in deep trouble."[2]

When the violence comes from within the family the child is even more vulnerable, for there may be no parent who can protect the child. Violence, or the threat to a child's basic safety, can come from within the family or from without. It crosses economic boundaries and is both an urban and a rural problem.

Children who are at risk do not inevitably end up with severe emotional disabilities. Some children who might be seen as having many risk factors working against their healthy development demonstrate a remarkable ability to thrive and to reach out for the support they need from whatever people and resources are available. Many families, particularly those with strong family ties, can overcome environmental risks and establish strong healthy coping strategies.

From a policy perspective VIC is concerned about those children who are exhibiting behavior or experiencing feelings that, to experienced observers, are clearly outside the range of "normal" development. Risk factors provide a framework for targeting or prioritizing problems and for targeting resources. Our goal is to describe how such children and their families can be helped in their own communities.

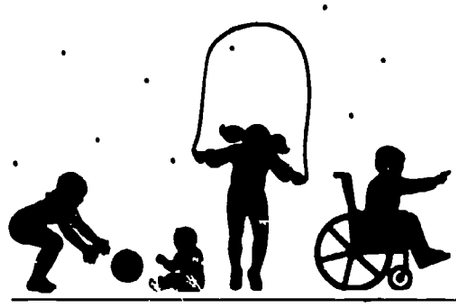


WHAT CAN HAPPEN TO CHILDREN WHO NEED HELP?

Consider, for example, a boy who becomes known by his kindergarten teacher as a "trouble maker." He is a child who cannot take directions, is often at the center of the group that causes trouble on the playground or in class, resents the authority of the teacher and talks back. His teachers will say they already know this child is headed for trouble, and often parents are told that this child is a "discipline problem." The parents are told that they must make the child conform and this fails to happen. As the child reaches second grade he is seen as having significant difficulty learning in a regular classroom and the child is labeled "behavior disordered" to explain or codify the problem; this is a special education category of children who exhibit significant emotional or behavior problems. Meanwhile, the parents may not recognize their child's behavior as cause for serious concern, and as the parents and teacher maintain their diametrically opposed view of the child, the child becomes caught in the middle.

By third or fourth grade this child's capacity to disrupt the class has the teacher so frustrated that she wants the child out of the class. Meanwhile, the family also has become increasingly frustrated because they know their child is not learning in a normal way for a child his age. By seventh or eighth grade this child has been banned from a regular classroom to a special education self-contained classroom at best, or at worst is rapidly becoming a youth heading for the growing number of school dropouts. The local police are noticing the child because they have picked him up more than once for vandalism, fire setting, acting out behavior in the community, terrorizing younger children, theft, or drug use. Now the child becomes involved with Juvenile Court on a delinquency petition.

This example could easily take place in a family, school and community that may well have some resources to offer. Now consider the experience for children who are in foster care, who live in dysfunctional families where parents have great difficulty in caring for the needs of their children, who live under conditions of extreme poverty where there are no resources in the community, or who attend schools that cannot meet the needs of individual children because of lack of resources and/or overcrowding. The impact on the child's behavior can be even more devastating.



WHY THE MENTAL HEALTH SYSTEM DOES NOT HELP THESE FAMILIES

The Department of Mental Health and Developmental Disabilities (DMH/DD) considers its primary mission "to assure that appropriate public mental health services are available and accessible to persons with severe and persistent mental disabilities . . . within that mission, the Department is committed to the development of a comprehensive system of services for children with severe emotional disturbances and their families."[3]

DMH/DD targets its responsibility to the 2% (65,000) of all Illinois children who are severely emotionally disturbed; i.e. those who have been hospitalized or who are at immediate risk of being removed from their home, school or community because of a severe inability to function for an extended period of time. These children are known as "severely emotionally disturbed" or SED children and have diagnosed mental disorders. Priority is given to children and adolescents needing services from more than one public agency but that does not necessarily result in coordinated services between agencies. This relatively small number of children and adolescents consists of children who are already in crisis, mostly older than ten, and usually involved with more than one state service system. There is general agreement that at least 10% to 12% of all children are experiencing significant mental health problems at any given time.

The official definition of this target population is children and adolescents who meet all five of the criteria which include: age, primary diagnosis, severe functional impairment, duration, and multi-agency need (see appendix).

There is continual discussion about the need for a range of available services, from prevention to residential treatment, that will help these children, yet almost every discussion is prefaced with the phrase "severely (or seriously) emotionally disturbed children." This trend has become so prevalent that we fail to notice that we are already at the "deep end" of the continuum; that within this context "prevention" means preventing extrusion from home, school, or community. We are losing the concept that an important meaning of prevention is to prevent a serious disability from happening or to lessen its severity. So we lose critical opportunities.[4]

The result is an approach that focuses on children and families in crisis. A crisis must be present before DMH/DD can respond; children and their families must be in crisis before they get help. We have become focused upon the problems and crises of mental illness and have not given due consideration to the opportunities and challenges of mental health. We have not paid enough attention to how these two ends of a continuum are related. It is as if we set up a Department of Public Health that only focused on cancer and chronic or life-threatening diseases and then stated that to be the limit of their responsibilities.

But there are many other children with mental health problems that threaten their well-being. The reality for most families is they face the problems of getting appropriate help alone. They will find some useful help in some cases and in others they will face years of growing frustration, anger and a sense of helplessness about their own abilities to get the help their child needs. Even the most resourceful families experience this frustration. In those families in which parents are less motivated to seek help or do not know how to help their children, the child is even more vulnerable.

WHAT KIND OF HELP DO CHILDREN AND THEIR FAMILIES NEED?

The most important need a young child has is a loving and nurturing relationship with at least one parent. At the most basic level children need to experience emotional attachments which evolve into a sense of trust that an adult, or several adults, can be counted on to provide consistent care. Without this attachment relationship that is critical to human survival, the child cannot develop an emotional core of self-worth and self-esteem. The child needs an environment in which he or she may develop physically, cognitively, emotionally, and socially. In order to do this, the child needs to experience a strong and safe attachment to a consistent caretaker. The emotional quality of this primary relationship is going to establish the emotional environment in which the child's development will take place.

The debate about the mental health of children should focus on what helps families raise healthy children. Such a discussion should not start by focusing on current state agencies and their narrow mandates. Those mandates define the particular services the agencies can offer particular clients. But families have a far different set of complexities to deal with and the interwoven strands of their lives cannot be separated to fit neatly into service categories.

For example, when a family is in trouble because of a parent's substance abuse the needs of the children cannot be met just by enrolling the parents in a substance abuse program. Often intensive in-home family preservation services are needed to help keep the children fed, clothed, safe from neglect or abuse, in school and supported emotionally. This type of family problem is not rare; for example, the state of Washington recently found that 66% of children identified as being severely emotionally disturbed had a family history of substance abuse.[5]

Parents need support for their efforts and recognition of the contributions only they can make to their children's healthy development. They have often been the focus of blame for what goes wrong in their children's lives. Many therapeutic models for mental health services focus on the deficits in the parents that cause problems for the child. While parental actions or inactions can trigger emotional problems in children, outside help must enlist parents and engage them to identify ways in which they can help themselves and their children.

The reason is simple. Parents are their children's only resource for large periods of time. Parents will only accept this help voluntarily if they have some say in the decision about what help they are given. Parents will also only accept help that, in their view, deals directly with their problems. When parents cannot or will not accept help, or when they are unknowing about the meaning of the child's problems, the first hurdle is to find ways to build an alliance with the parents focused on recognizing that the child needs help and how to obtain it.

Programs that help children and families need to be accessible. Programs and services need to take place in settings where people feel welcome. They must also reach out to those families who want help but do not know how to get help or who are least likely to reach out for help on their own. Many young parents, first-time parents, parents living in economic deprivation, and parents of children with disabilities feel very isolated and alone with their problems. They feel cut off from even their own families, friends, and neighbors, having no one to turn to and not knowing how to ask for help. They often do not know where to go for help. Programs which seek to identify families in need of help, which offer help in places where children and families ordinarily go, and which give the explicit message that it is all right to ask for help are crucial in enlisting families to help themselves.

Some parents face underlying problems of poverty, lack of education, teenage parenthood, and the need for resources to meet basic survival needs. Parents who lack basic parenting skills can benefit from parent education programs but it is critical that these programs recognize and respond to the parents' cultural or ethnic background. It is also critical that they offer practical help the families want; otherwise parents will leave the programs frustrated and angry.

When help requires resources from more than one agency, case management becomes very important. Case management identifies one person as responsible for helping a family plan what they need and how to get what they need when confronted with many different systems or resources. Case managers help people through the maze that can overwhelm someone needing help and they can encourage families to persist in taking the next step. The family is supported and helped when one person works with them to sort out where to go for what help.

Parents of children with chronic disabilities need help in managing the complexities of the child's care, skills to cope with the extra demands of raising a disabled child, support from other such parents, and respite care. They also need to learn how to advocate for their child and demand the resources they need. They need recognition that their fears and concerns about their child are often reasonable.

Sometimes when the parents find it difficult to help their child, significant help should go directly to the child. The children of parents with mental illness or drug addiction, for example, may need interventions that provide developmentally appropriate stimulation for them, in ways that the parents cannot, to further their normal cognitive/emotional development. Sometimes it may not be possible to get such change by focusing on the parents in hopes that they will change.

Children who have severely dysfunctional parents and children who are in substitute placement are at the greatest risk of not forming a primary attachment in their young lives. The need for a permanent family is at bedrock for every child. The mental health implications for any child who enters foster care are, therefore, extremely important.

It is the purpose of the Children's Mental Health Project to identify "windows of opportunity," for both child and parents; these are circumstances when existing institutions and resources can be refocussed to provide help that is timely, relevant and acceptable. We must be concerned not only with those children who have the most severe disabilities, but also with those children who are at significant risk of developing more severe dysfunction if the current conditions facing them and their families are left unattended.

WINDOWS OF OPPORTUNITY

- HELP FOR FAMILIES:
  LOOKING FOR OPPORTUNITIES
- OPPORTUNITIES

WINDOWS OF OPPORTUNITY

HELP FOR FAMILIES: LOOKING FOR OPPORTUNITIES

The past 10 years have seen a host of exciting discoveries about how infants receive information and how they interact with the world around them. The accepted wisdom has moved from thinking that babies were relatively passive receivers to a growing understanding that infants are born with complex capacities, both physical and emotional, which under normal circumstances develop rapidly. The emotional and social development of the healthy infant is now believed to be dependent upon the process of "bonding" between a primary caregiver, most often the mother, and the baby. The work of researchers has documented that infants are aware of their mothers almost from birth.[6]

The caregiving relationship provides the young child with an emotional communication system. The emotional, cognitive and social development of the young child are inextricably linked to this primary relationship and anything that threatens the healthy development of the relationship also threatens the healthy development of the child.

Pressures on families are increasing. Pressures on families result in pressure on children. In some families this can lead to abnormal development. The family is the major influence on children's development during the early years and if they can be helped early, there is the possibility of having a positive impact before the child develops a more severe problem. Divorce, single parenting, poverty, working parents, out-of-wedlock births, teenage parents, and substance abuse make it more difficult for parents to nurture young children and promote their social and emotional development.

The very young child is particularly vulnerable to a stressful environment. Since normal development proceeds rapidly, when normal development is interrupted young children need prompt attention. Early intervention first requires the identification of children who need help. Then it requires the provision of the range of appropriate help in the child's community. Particularly with very young children, prevention and interventions may come from programs not identified as primarily mental health in focus or purpose.

The goals of prevention and early intervention are to lessen the incidence and reduce the severity of serious emotional disturbance. The aim is to keep the greatest number of children possible developing normally. Prevention provides opportunities to keep a child healthy, and early intervention can prevent further decline for many children who begin to show signs of emotional disturbance. Young children who exhibit mental illness caused by organic abnormalities will benefit from early intervention which not only addresses the child's needs but can support the family in raising the child.

Families whose children have mental health problems need support services that will increase their capacities to cope. These support services should include advice and counseling at home or at a community location, parent-child centers which provide programming and drop-in activities, parent self-help groups, appropriate child care, and preschool. A variety of community sponsors and organizations can provide these services. If these organizations are connected in an accessible network, families will find it easier to get the help they want. Otherwise families are the losers in the organizations' scramble to maintain their separate domain. Families need help in identifying where to go to get what they need. An effective and appropriate referral process is a key component.

Parents in every community in the state need to know where to get help. The goal is for e very community to have a mutually supportive network, which is backed up by mor specialized expertise when that is appropriate. Families who recognize "somethi g is wrong with my child" must be able to find qualified professionals who respond by acknowledging the validity of the parents' concerns and by including the parents in a partnership to find appropriate interventions. Parents need validation that they do indeed know their child and they are critical participants in successful interventions. Networks should be broad enough to allow a family the possibility of finding this relationship between parent and professionals, or to be able to choose another option if they feel their child is not getting the help he or she needs.

Many communities already have resources that help families raise their children. Most of these, however, are not particularly sensitive to the needs of emotionally disturbed children. With extra training and encouragement these existing sources of help could help families with troubled children. We now describe a number of these opportunities.

OPPORTUNITIES

Opportunity: Medical/Health Care

At the very beginning of a child's life, there is often contact between the parent(s) and a doctor, nurses, midwife, hospital social worker, and sometimes a visiting nurse. This may be the only contact parents have with community resources outside of family, friends or neighbors. Here is the first opportunity to pick up on concerns for the new baby's future and the capacities of families to take on the role of parents. This is also a situation when asking for help is part of a normal transaction. During the pregnancy a professional can also begin to identify families that may need some extra help after the birth of a child and suggest some sources for that help. During prenatal care parenting skills can be taught, feelings about the child brought forth, and awareness about the child's needs developed.

During even a short hospital stay there will be a few opportunities for teaching new parents about their child.[7] In the post-natal period a program that provides for home visits by a public health professional has the opportunity to reach out and engage parents around ways to nurture their child within their own environment.

A public health home visitor who is credible as a person and who can provide practical help in a way that does not label the child can make a general assessment of the coping capabilities of the parent(s) and the developmental progress of the child. During such visits parents can be shown the importance of playing and talking with their babies to stimulate their child in small ways. Health visitors will have an advantage if they reflect the cultural backgrounds of the communities in which they work.

In those families which are very dysfunctional or where the baby's development or behavior is cause for concern, the home visitor can link the family with additional sources of help.

"Lessons from the Child Survival/Fair Start Home-Visiting Programs," an evaluation of five home-visiting programs in six states, identified as a key component of successful programs: "listening to the people the program will be serving . . . the actual conditions of their lives, the needs that most concern them, the strengths they can call on."[8] The evaluation also stressed the importance of developing programs around local traditions and styles of interaction.

A home-visiting program within a health care context can make a specific effort to focus upon parenting and child development. The priority components of home-visiting programs include:

- Enhancement of parenting skills
- Informal teaching about child development
- Helping parents cope
- Lending emotional support and encouragement
- Sharing useful information
- Lessening the sense of isolation
- Screening and assessing the child's physical, emotional, cognitive, and social development
- Supporting parents who face very difficult problems with severely developmentally delayed or medically at risk children
- Knowing the community and its resources
- Involving those using the programs in program design

There are several practical problems that need to be solved before this opportunity can be exploited fully. They include:

- Currently there is a shortage of visiting nurses and trained home visitors.
- Health visitors often need additional training in a child development and a mental health perspective.
- Funding patterns for current initiatives are extremely fragile and even an effective program can have its funding cut after the initial start-up phase.
- One of the goals of this kind of initiative is to help build a self-help and support network. Parents need to be encouraged to develop their own ties to extended family, neighbors, and friends. Then when the home visiting program stops the family need not return to its former sense of isolation.

Opportunity: Child Care

Child care is the next most likely contact for a family with very young children. About 667,000 Illinois children aged 0-5 have working mothers.[9] Quality child care can enhance the psychological and social development of a child; poor quality care can threaten that development and can exacerbate the impact of existing problems.

The varieties of child care include home care (where a relative or unrelated person comes to the home of a child or the child is taken to a caretaker's home); center-based care (where the child joins other children in a sponsored program); or family day care (where several children are cared for in someone's home). Often for the working parents the cost of the care and the proximity to either home or work are overriding factors in selecting child care.

Parents may need encouragement and help in understanding the importance of age appropriate care for their child. For an infant, a primary concern is supporting the secure attachment infants need with their parents. Quality child care will involve the attention, affection and continuity of a caretaker that babies need when they have to be away from their working parents. From a mental health perspective, child care that is solely custodial, and which does not meet the emotional and developmental needs of a child, puts the child at risk.

A few young children stand out in congregate settings because of their unusual behavior. Well-trained staff in a day care program can identify the children who are in trouble and who are developing emotional problems. A good child care program should include parent education, consulting to staff by trained mental health professionals, and the possibilities of early intervention with families to help them with children who need extra patience and attention.

The priority components of good child care are:

- The care is developmentally appropriate for the child.
- The care provided supports the parent/child relationship.
- The importance of the relationship between a child and the caregiver is recognized.
- The staff are trained and experienced in child development so they can provide a developmentally appropriate program.
- The staff understand that certain child behaviors are well outside the normal range and require particular attention.
- The few children with special needs are provided with appropriate specialized child care.
- The staff remains consistent which helps to sustain the young child's ability to form attachments.

Opportunity: Child Welfare Services

In 1989 there were 19,027 Illinois children living in foster care and the number is expected to rise to 22,500 or more by the end of 1991.[10] In 1988, children under five were the fastest growing population of those entering foster care for the first time, and made up 47% of all children entering care. In 1989, 25% of children entering foster care were under the age of one.[11]

These children are at considerable risk. They are at risk because of the initial circumstances that brought them into care, circumstances that range from poverty and homelessness to severe neglect from parents who are unable to cope, to abuse and in-utero exposure to drugs or alcohol. Some of these risks have long term consequences for the children's development.

The act of bringing children into foster care often exacerbates their problems. They are separated from parents many of whom, whatever their other shortcomings or problems, loved their children and gave them some measure of emotional support. Many children return home from care in a short period of time, but those who do not can pass through a succession of foster homes in short order. Children who slip through the cracks of the child welfare system and receive little consistent care sometimes end up in the juvenile justice and mental health systems.

The most critical emotional need of foster children is to be placed in a permanently supportive family so that they receive consistent nurturing in a mutually rewarding relationship. It is now well established that a child welfare department's first priority should be to keep children in their own homes where that is consistent with the children's well-being. The next priority is to return a child from foster care as soon as possible. If a family proves incapable of caring for their own children, those children should be placed in permanent homes, either adoptive or long-term foster homes.

The Illinois Department of Children and Family Services (DCFS) has responded to these goals in its Family First and Family Reunification programs. The Family First program is an intensive intervention effort to stabilize families in crisis with the goal of keeping children at home who are at risk of placement. The program specifies a range of services including homemakers, emergency cash assistance, individual and family counseling, and parenting and child development education.

The dual challenge to DCFS is to expand the availability of the Family First Program and to ensure that the services are relevant to the needs of the family. An evaluation of this initiative is underway and should clarify which families can be helped by intensive short-term interventions. The Family Reunification program has just started and faces the same challenges as the Family First program.

Children in the child welfare system who are placed in appropriate permanent homes may still need additional help. A study of children taken into DCFS custody in Cook County found that 52% of the children three years of age and younger were in need of infant stimulation programs.[12] The same study found indications of developmental delays in 38% of the children who were zero to five years old. DCFS children as a group also have a higher incidence of learning disorders than the general population.

A report by La Rabida Children's Hospital and Research Center found that even when a child had been identified as having a mental health problem that required therapeutic services, those services were often not provided. "In general, outpatient psychological service recommendations were not followed as frequently as other service recommendations. Family psychotherapy, individual psychotherapy (child), and additional psychological/psychiatric assessment were obtained 44%, 35%, and 29% of the times they were recommended, respectively."[13]

DCFS has the opportunity and the responsibility to provide its wards with the range of developmental and emotional help they need At a minimum, wards who qualify for such programs as early intervention services, Head Start, special education and counseling services should get them in a timely fashion.

An effective child welfare system concerned with its wards' mental health would:

- Maximize the number of children who can appropriately stay at home.
- Move wards of the state to a nurturing permanent home as quickly as possible.
- Ensure that all children who require developmental support, special education, and counselling receive appropriate and timely help.
- Give extra support to both natural parents and foster parents whose children require special attention.

Opportunity: The Community-Based, Family Support, Drop-in Center

Family support drop-in centers provide a meeting place for children and parents, community members and trained staff. In an informal setting there can be valuable exchanges between peers and between trained staff and participants. Young children can play with their peers and staff can, by example and suggestion, increase the parents' capacity to care for their children. The feelings of isolation and lack of upport which are often present in troubled families can be addressed directly or indirectly.

Local support programs can help a mother's relationship with her child. Encouraging mothers in such basics as smiling, vocalizing and playing with their young children can have important outcomes in the development of the child. The simple example of showing a young mother how she can get her child to smile or giggle will, in turn, give her confidence that she can help the child to feel pleasure. This simple interaction, a most basic human exchange, is but one crucial building block for the future mental health of the child.

The staff can also advocate for the needs of the families in the community, make referrals for those who need mental health services, and educate the community about the needs of its families. The importance of reaching out to families needing help cannot be over emphasized. Often the most troubled families will not seek help without encouragement. Such community-based programs in some areas are the closest available resource to a family which needs help.

Many families will not seek out "mental health" services because of the stigma attached to mental illness. Some parents will, however, bring their children to a family support and drop-in center program because they would like to have their child better prepared for school and because the mothers are often lonely. The informal nature of these programs can offer opportunities for parents to share and begin to support each other.

These dynamics are particularly important in communities organized around cultural norms different than those of the majority culture. The environment, activities and relationships can reflect the strengths and values of the neighborhood culture, which in turn will help build self-esteem in the children. The goal of these programs needs to remain focused upon helping and empowering parents, thus identifying their own strengths and capacities to be responsible for their own children. One center director attributed the success of her program to respect for the parents: "Parents take control of their own lives by learning how to take control of this place."

A key component of any community-based program is that parents have input in its design. To be successful it needs to be shaped by the families in the community so a feeling of local responsibility is developed. Evaluation research on family support programs in high-risk communities suggests that successful programs are developed through negotiations among key participants. Often staff, administrators, and families will not agree about how to meet the needs of participants and the negotiation process will take some time.[14]

In a neighborhood confronting a combination of extreme poverty, drug use, violence and lack of community resources even the best family support center is not enough. For parents who are consumed by the most basic survival needs, child development strategies may appear irrelevant. The priorities for such families are a safe environment and an adequate income.

In the most desperate communities, family support services can only be a band-aid and at some level of harshness, the first priority for families has to be a safe environment and adequate income.

Opportunity: Community Mental Health Centers

An estimated 34,000 Illinois children from 0 to 21 years old receive outpatient services from their local Community Mental Health Center (CMHC).[15] Children and their families may seek help from a CMHC on their own or may be referred by someone else. Services are offered on a sliding scale fee basis. Clinics having trained child and adolescent staff can be an invaluable resource to other community based programs. However, not all CMHCs have staff specifically trained in child and adolescent services. Working with children requires knowledge and skills different from working with adults. Children are more pliable than adults and can make larger adjustments - this is the opportunity. However, children are dependent upon the adults in their lives and successful treatment of children requires some level of collaboration with the parents. Outpatient services require an understanding of what is going on with the child, the parents, and the family.

CMHCs can provide a range of services from prevention to early intervention to crisis intervention. Such services can include assessment and diagnosis, consulting to other community resources, parent education or self-help programs, outreach, case management, primary prevention programs, and raising the public awareness of mental health needs and services. More concretely CMHC staff can consult with day care centers by observing classrooms, participating in case and on-site parent conferences with the center staff, aiding in screening for developmental delays, providing skilled professionals to work with the challenges of a child with major disabilities, and helping troubled families learn coping skills.

Many Illinois CMHCs, however, are under siege. Their services are not available in many parts of the state. They have inadequate staffing in child and adolescent services and inadequate funding. Their priority clients tend to be the adults. When they do initiate a pilot program for children, they often depend on temporary funding from a foundation or a precarious patchwork of sources which can easily dry up. Some CMHCs express concern about the unreimbursed cost of counseling children and families who are under the care of the Department of Children and Family Services (DCFS); some express concern that DCFS will not let the child be seen on an on-going basis, that treatments are ended abruptly by the Department, or that DCFS will not let the child be seen at all. They are often discouraged from providing any prevention-focused or early intervention services. Much of their time and resources are spent on people in crisis or on chronically mentally ill adults. This emphasis reinforces the perception that these clinics are only for those who are severely mentally ill and some families may well avoid using them to avoid that stigma.

Community mental health centers were designed to respond to children as well as adults. But they have not responded to children and their parents very creatively. The Department of Mental Health and Developmental Disabilities should, as a priority, re-examine the incentives and disincentives that affect CMHCs' capacity to help young children and their families.

Opportunity: Head Start and Children at Risk Preschool

Head Start, the federally funded program for preschool children, currently serves 22,500 Illinois children and will expand significantly as a result of changes in the FY 1991 federal budget. Children at Risk of Academic Failure, Illinois' state-funded preschool program, is serving 19,000 children in 1990.[16] Many other Illinois children are enrolled in a variety of privately funded preschool programs.

There is evidence that Head Start promotes positive social behavior in early school years. This in turn creates positive expectations in the classroom teacher, which in turn encourages positive behavior in the child, building confidence and self-esteem. The importance of this dynamic should not be underestimated in the early primary education years.

The work of Dr. James Comer with inner-city schools[17] has focused attention upon children who begin school exhibiting behavior which reflects underdevelopment or which is inappropriate in school. "The key to academic achievement is to promote psychological development in students, which encourages bonding to the school."[18] Critical dynamics in a child's first years in school are the child's, parent's and teacher's expectations of what school is about, and what behavior is appropriate, and the expectation that success is possible. When a child enters school and finds an unfamiliar, unpredictable or negative environment, too often a pattern of behavior is established that is perceived by the teacher as negative. Far too often this can set up a chain of events that can lead to the child being labeled "behavior disordered" by second or third grade.

Like Head Start, Dr. Comer stresses the importance of the parent-child relationship in preparing the child for the "culture" of school. If the home environment and the school environment have no shared values in common, then the child is forced to make a choice between the two, which is more than a child can do. Preschool programs which bring parents into the program, reflect the culture and values of the families within a community context, and help to enable the healthy development of children set the child up for a successful transition to school and between family and school.[19]

Head Start includes two mental health components in its program performance standards. The first is to "assist all children participating in the program in emotional, cognitive and social development toward the overall goal of social competence in coordination with the education program and other related component activities."[20]

This objective clearly implies the inter-relatedness of children's capacity to learn with their emotional and social capacities. The second component states: "The mental health part of the plan shall provide that a mental health professional shall be available, at least on a consultation basis, to the Head Start program and to the children."[21]

Program activities would include staff training, staff consultation, direct involvement with parents, and screening, evaluation and intervention recommendations concerning specific children. In addition to these mental health program components, Head Start requires that 10% of the children enrolled in a program be children with disabilities. Children with severe emotional and behavioral problems are to be included in this designation. Head Start can have a special impact in rural communities where families can become isolated, where poverty is growing, and where specialized resources can be very scarce.

Another fundamental concept of Head Start is the importance of parent involvement. This includes parent participation in the program and its development, parent education, home visits by program staff, and providing parents with an understanding of how children grow and develop. This level of parent participation holds promise for helping troubled families cope with their problems. A focus on family advocacy helps parents of children with disabilities, including emotional or behavioral ones, learn to identify what their children need and how to get help.

The state-funded Children at Risk preschool program currently does not contain any mental health standards similar to those of Head Start, nor does it require that 10 percent of its program openings be filled by children who have disabilities. The range of parent involvement varies widely and in a recently published report "All Our Children Can Make the Grade," Voices for Illinois Children called upon the Illinois State Board of Education to "establish guidelines that describe the range of practices that constitute effective parent involvement, and monitor that involvement more closely."[22] The State Board should also establish standards for a mental health component in preschool programs and encourage and monitor the enrollment of children with disabilities in the preschool classrooms.

Even with the expected federal expansion of Head Start, more than half of Illinois' three to five year olds who are eligible for publicly funded preschool will not have the opportunity to enroll in such a program. The state preschool program should be expanded to meet more of this need.

Opportunity: Preschool Special Education

The Federal Education For All Handicapped Children Act (1975), known as P.L. 94-142, guarantees a free and appropriate public education in the least restrictive setting to every child no matter what the child's handicap. Handicaps are defined to include physical, cognitive and emotional disabilities.

Services under P.L. 94-142 include speech/language therapy, special materials/equipment, counseling, psychological services, special transportation to school, parent counseling which teaches natural and foster parents how to care for children with disabilities, specially trained teachers and aides, and education programs longer than the normal school day or school year.

To ensure that the education provided is individually appropriate, each child is required to have an Individual Education Plan (IEP) which considers the child's abilities and educational needs. Parents are to be involved in every decision affecting their child. Special education programs are offered in individual school districts under the State Board of Education for children aged three through 21. (An amendment to P.L. 94-142 known as P.L. 99-457 extends the state's responsibilities to include children between the ages of birth and three and will be discussed in the next section.)

It is the responsibility of each local school district to actively seek out, identify and evaluate children with disabilities from birth to age five who are eligible for special education services.[23] The fulfillment of this responsibility requires the active participation of the school in the network of community resources for families with young children.

Again, family involvement is a crucial element of the success of special education. Special education staff must act in ways which help families maintain or develop a sense of their own strengths, abilities and feeling of control about their child's life. An IEP should maximize child's participation in education and community life in the least restrictive setting. Children with special needs should be involved with children without special needs in as many situations as possible.

It is important that when children change programs as they grow older the transition is managed in ways that maximize their sense of disruption and that minimize the intrusion of bureaucratic processes in their lives.

A child's entry into the special education system adds a label or a set of labels to a child's identity. Such labels might change parents' or teachers' attitudes toward children in ways that harm the children's sense of themselves. The anticipation of this process might even dissuade a parent from seeking help.

This almost inevitable process is one of the reasons why children with special needs should interact with the rest of their peer group as much as possible, and why any description of special needs children should, as a matter of course, emphasize their particular capacities and strengths.

Opportunity: The Possibilities of P.L. 99-457

In 1986 a new federal law, Public Law 99-457, established a set of amendments to the Education of the Handicapped Act (known as P.L. 94-142 and established in 1975). P.L. 99-457 creates a comprehensive system of identification and early intervention services to address the developmental needs of all eligible children during their first three years of life. The law provides for planning funds to each state that promises to implement such a system over five years.

Eligible children are 1) those with measurable developmental delays, 2) those with conditions which place them at high probability of developmental delays, and 3) possibly those children who are at risk of substantial developmental delays. The first two categories are mandated; the third is optional at the discretion of the individual state.

An individual child's eligibility will be determined by a thorough interdisciplinary evaluation of the child's cognitive, physical, speech/language, pyscho-social, and self-help development. Developmental delay in any of these areas makes a child eligible for early intervention services. Early intervention services include home-based therapies, for example, motor or speech delays, parent support and education efforts, and respite care for parents who care for children with severe disabilities.

The federal law mandates the use of an Individual Family Service Plan (IFSP) which spells out agreed upon early intervention services needed by the child and family. Each IFSP will identify a case manager for the family and will spell out the who, what, when, where, how, and why of services needed, including transportation when appropriate. At the heart of this process are the principles of building on family strengths, supporting family efforts, and involving parents as partners.

Sometimes physiological delays are easier to recognize, accept, and work on than emotional and social delays. But these latter delays can have just as serious effects on a child's capacity. It is the intent of the federal law to encompass all types of delay and it is important that mental health issues receive adequate attention.

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A recent National Institute of Mental Health issues paper states, "Just as emotional and mental health are critical to the overall development of children and families, so are the insights from mental health disciplines, the skills of mental health professionals, and the resources of mental health agencies crucial to the effective implementation of P.L. 99-457."[24]

The decision about extending eligibility to children "at risk of having substantial delays" is currently being debated in Illinois. There are strong arguments for including such children in the definition of who is eligible for early intervention services: 1) Such children are most likely to respond to early intervention. 2) If such services are indicated for a child, the services are likely to be simple and inexpensive. 3) The inclusion of such children is our important backstop to the professional judgement of the interdisciplinary evaluation team. It acknowledges the fact that current formal evaluation instruments are still too imprecise for satisfaction and that there will be children at risk of substantial developmental delay who can not easily be diagnosed. 4) A narrower definition poses the risk of an early intervention program minimizing emotional and social developmental disabilities while focusing on cognitive and physical delays.

The declaration that children experiencing emotional and cognitive delays should receive help will not, of course, guarantee that they get help. Unless the councils and case managers who run a community's early intervention network are skilled in detecting and responding to children with significant emotional and social interaction problems the new system will not help those children. Moreover, unless the service providers are prepared to meet the children and families in those families' own worlds, (in the home, the day care centers, the school or the recreational program) their intervention is likely to be under utilized and less effective.

Opportunity: Medicaid Funding for EPSDT

EPSDT, the Early and Periodic Screening, Diagnosis and Treatment program ("Healthy Kids" program in Illinois) is a part of the Medicaid program. Medicaid is a federal entitlement program which provides a federal dollar match for every state dollar spent on eligible services for eligible people. In Illinois, the Healthy Kids program is administered by the Department of Public Aid.

In 1989 Congress, through the Omnibus Budget Reconciliation Act, made significant changes in EPSDT. These took effect in April, 1990, and include:

a) the expansion of eligibility to pregnant women and children under six whose annual income is up to 133% of the poverty level (over $16,000 per year for an Illinois family of four),

b) the expansion of Healthy Kids services,

c) mandated increases in provider compensation to reach equivalency with local private providers, and

d) increases in the range of eligible providers.

The changes require that a health screening must include the child's health and developmental history (both physical and mental) among other items. Virtually any physical or mental problem discovered in an EPSDT screening must be diagnosed and treated. Treatment includes therapy, therapeutic child care, case management, and transportation. Treatment can take place in the child's home, foster care homes, clinics, child care sites, schools, hospital outpatient units, and private offices. The provider expansion means that anyone who can provide a Medicaid-eligible service can now be enrolled as a Healthy Kids provider. These changes mean outpatient mental health services can now be included in Healthy Kids.

Illinois, however, must change its Healthy Kids program if mental health services are to be included in ways intended by the OBRA legislation. As of November, 1990, Illinois made no special provision for the inclusion of mental health, early intervention, or developmental disability clinics in the Healthy Kids program. Illinois does not include the services of licensed nurses, licensed psychologists, or licensed social workers in its program. Nor does the state provide for outpatient mental health visits, except with a psychiatrist, or targeted case management for early intervention. Illinois provides no guidance on screening for infant mental health.

EPSDT is a major potential source of funding for a comprehensive system of early intervention services as provided for in P.L. 99-457. The federally funded National Early Childhood Technical Assistance System has estimated that 30-50% of all children eligible for early intervention will be Medicaid eligible and that Medicaid can pay for 90% of the early intervention services needed by these children.[25] However, to make the changes described above, the system needs to maximize the effectiveness of the mental health aspects of early intervention and the state will need to make significant changes to its Medicaid program to adopt and implement these innovations.

Opportunity: Advocacy

A fundamental challenge facing child advocates today is to change the limited vision of an approach which attempts major change by repairing, or otherwise "fixing" the system. This puts the system at the center of the discussions when the needs of children and their families should be there. We have many layers of providers, bureaucrats, advocates, consumers, and legislators constituting the current system; more of those people must focus their discussions on what can help children and families. We need input and guidance from parents who can tell us about their needs, communities, and cultures. We need to stress outreach, home-based and family support services.

We need to focus upon those families who constitute the working poor and whose incomes just ex ed financial eligibility criteria for subsidized services. These families are unde the stress of trying to make ends meet. If they are faced with the added burdens of a disabled child, they could be worse off than families who meet eligibility criteria for such services as Medicaid or Head Start. The cost of good child care can simply be out of reach.

The challenge to advocates is to ask the following questions about any program:

- Does this service really help children and their families?
- How can we learn from families what would be helpful?
- How can we build on the strengths families have?
- How can we strengthen the social fabric of a community, so that living there wil pport the healthy development of children?
- How can we encourage shared community values and a shared sense of community responsibility towards investing in its children's future?

The growing body of knowledge about infant mental health, mental health in the young child, effective early intervention programs, the impact of poverty, the prevalence of substance abuse, and other factors which place children at risk give us some opportunities and information which may help us constructively plan ways we might help. We cannot wait until we have an older or a more severely disturbed child before we recognize the need for effective mental health programs.

A difficult challenge is fixing attention on the mental health needs of children. Frequently the mental health debate and resources are focused on adults. There is the additional challenge of getting people comfortable enough with the concepts of mental health and mental illness to engage in an open debate.

The challenge is not how many planning councils we can create or how many plans we can write, but how we will implement and pay for what we already know works. We know that a child's psychological and social development has tremendous impact on who children become, how they learn, what they will need from society, and what they will be able to give back.

Prevention and early intervention must become a focus in the state of Illinois. At birth, mental health has already been affected by the conditions of the pregnancy. Therefore, good prenatal care becomes an essential prevention component. From this point on children have emotional needs which can be met either in ways that lead to emotional health or in ways that can lead to emotional disturbance. No system that focuses only on the one to two percent of all children who have been identified as functionally severely emotionally disturbed is a system of "mental health."

CONCLUSIONS: INCREASING THE OPPORTUNITIES FOR HELPING FAMILIES

Mental health programs for children and their families should be based upon the principles of children's healthy development. A child development model includes consideration of how children actually grow and what their needs are at different stages. In this model age; relationships, especially with parents; and developmental priorities of children should be the basis for the design of services. Prevention, early intervention, and interventions for severely disabled children must take into consideration a range of needs from mental health to severe mental illness, rather than focusing solely on illness and crisis.

The needs of the child and his or her family must drive the system. This means that the concrete situation of families, their capacities and difficulties should drive the construction of programs and the allocation of resources.

Poverty, homelessness, violence, and drug abuse pose threats to the very survival of children and are clear risks to children's mental health. In the most desperate communities, family support services can only be a band-aid and at some level of harshness, the first priority for families has to be a safe environment and adequate income.

But, when families are in less desperate circumstances, local help and support for raising a troubled child may make the difference between the child's condition deteriorating or improving. Occasions for providing such help already exist in the opportunities we have described in programs ranging from Head Start to drop-in centers and day care centers. The next step is for the staff of these organizations to receive training in identifying and responding to children with emotional difficulties in ways that help the parents cope a little better. If this happens, the children can receive attention before this condition deteriorates to the point where it threatens their ability to cope with kindergarten or first grade.

Among the most vulnerable children are foster children in the DCFS system. DCFS should pay careful attention to the developmental needs of children in its care. When a child's placement plan focuses only on the circumstance of who will parent the child and where the child will reside and does not address the developmental needs of the child, it is seriously incomplete. It is imperative that these children get the benefit of appropriate early intervention programs.

VIC's analysis shows that responsibility for providing mental health resources is a far larger task than that performed by DMH/DD. But the Department of Mental Health and Developmental Disabilities should have some designated responsibility for promoting prevention and early intervention services focused on young children's mental health. The Department has a statewide planning process for the most severely disturbed children. The Department should also be planning for the mental health needs of less severely disabled young children who could benefit from the local help described in this report. The primary goal of such DMH/DD planning should be to reduce the incidence, prevalence and severity of emotional disabilities in children.

P.L. 99-457 (early intervention) presents a significant opportunity to establish a new level of collaborative, family and community based network of services to those young children who have the greatest need. The federal goal is for each family with a child who is developmentally delayed or at significant risk of developmental delay to have access to an appropriate network of early intervention services in their community. Early intervention programs should include services that range from physical therapy to cognitive development. It is critical that mental health services are part of the mix.

Our goal is to encourage avenues of support that can work for different families, in ways that are useful to them. When families sense that a young child is troubled they should know where they can go for help in their community. Community based professionals should be able to respond to young children's mental health problems in ways that enable parents to help their children. Young children should get help before their problems threaten their chances of coping with the demands of elementary school. Also, it is important to identify those children who are going to have long lasting mental health problems and to offer support and resources to those families who face the challenge of raising a child with severe disabilities. The earlier in life such help can be offered, the smaller the cost to society, and the less the cost in human suffering.

ENDNOTES

1. Mark Testa and Eddie Lawlor, *State of the Child: 1985.* Chicago: The Chapin Hall Center for Children, University of Chicago, 1985, pp. 73-74.

2. James Garbarino, Ph.D., *Testimony to the U.S. Senate Committee on Human Resources, Subcommittee on Children, Family, Drugs, and Alcoholism,* on behalf of The Erikson Institute for Advanced Study in Child Development, April 3, 1990.

3. *State Mental Health Plan.* Springfield: Illinois Department of Mental Health and Developmental Disabilities, September, 1989, p. 5.

4. DMH/DD funds early intervention services for some children with developmental disabilities or significant developmental delays through its developmental disabilities programs.

5. *Forgotten Children: The Mental Health Needs of Washington Children, A Systems Analysis.* Seattle: Division of Community Psychiatry, Department of Psychiatry and Behavioral Sciences, University of Washington, August, 1988, p. 4.

6. For further discussion and readings, see:

   T. Berry Brazelton, *On Becoming A Family: The Growth of Attachment.* New York: Dell, 1981.

   Stanley Greenspan, M.D. and Nancy Thorndike Greenspan, *First Feelings: Milestones in the Emotional Development of Your Baby and Child.* New York: Viking, 1985.

   Daniel N. Stern, *The Interpersonal World of the Infant: A View from Psychoanalysis and Developmental Psychology.* New York: Basic Books, 1985.

7. A further discussion of the theoretical basis, clinical model, and case illustrations can be found in Ida Anne Cardone and Linda Gilkerson, "Family Administered Neonatal Activities: An Exploratory Method for the Integration of Parental Perceptions and Newborn Behavior," *Infant Mental Health Journal, vol.11,* Summer, 1990, pp. 127-141.

8. Mary Larner, Ph.D., High/Scope Foundation, "Lessons from the Child Survival/Fair Start Home-Visiting Programs." Presentation to the American Public Health Association, Boston, November, 1988, p. 3.

9. This represents approximately 57% of all Illinois children aged 0-5. *A Children's Agenda: Into the '90s.* Chicago: Voices for Illinois Children, 1989, p. 7.

10. In 1987 there were 14,395 children in substitute care. DCFS projects there will be 22,503 children in substitute care in 1991. Illinois Department of Children and Family Services, "FY 91 Budget Briefing." Springfield: IDCFS, February 26, 1990

11. This information is from a telephone conversation with Robert Goerge, The Chapin Hall Center for Children, University of Chicago, January 10, 1991.

12. Neil J. Hochstadt, Ph.D., Paula K. Jaudes, M.D., Deborah A. Zimo, M.D. and Jayne Schachter, Ph.D., "The Medical and Psychosocial Needs of Children Entering Foster Care," *Child Abuse and Neglect, vol.11,* 1987, pp. 53-62.

13. Neil J. Hochstadt, Ph.D. and Neil J. Harwicke, Ph.D., "How Effective is the Multidisciplinary Approach? A Follow-up Study," *Child Abuse & Neglect, vol.9,* 1985, pp. 365-372.

14. Robert Halpern and Mary Larner, "The Design of Family Support Programs in High Risk Communities: Lessons from the Child Survival/Fair Start Initiative," *Parent Education as Early Childhood Intervention,* Douglas Powell (Ed.). Norwood NJ: Ablex, 1988, pp. 181-207.

15. The number of children receiving outpatient services is estimated by DMH/DD because the tracking system permits the possibility of assigning a code designated for children or a code designating an adult (parent) who may be seeking help for the family.

16. *All Our Children Can Make the Grade: A Report on the Illinois Preschool Program, Children at Risk of Academic Failure.* Chicago: Voices for Illinois Children, 1990.

17. The School Development Program was established in 1968 as a collaborative effort between the Yale University Child Study Center and the New Haven School System. See James P. Comer, M.D., "A Brief History and Summary of the School Development Program." New Haven, CT: Yale Child Study Center, March 1988.

18. James P. Comer, M.D., "Educating Poor Minority Children," *Scientific American, vol.259,* November 1988, pp. 42-48.

19. Norris M. Haynes, James P. Comer and Muriel Hamilton-Lee, Child Study Center, Yale University, "The School Development Program: A Model for School Improvement," *Journal of Negro Education, vol.57,* 1988, pp. 11-21.

20. "Head Start Program Performance Standards." Washington, D.C.: U.S. Department of Health and Human Services, Office of Human Development Services, November, 1984, p. 33.

21. "Head Start Program Performance Standards," p. 34.

22. *All Our Children Can Make the Grade: A Report on the Illinois Preschool Program, Children at Risk of Academic Failure,* p. 4.

23. "State Plan for the Education of Handicapped Act, EHA Part B." Springfield: Illinois State Board of Education, July, 1990, Section IV, A(4)(b).

24. Emily Schrag, "Sensitivities, Skills and Services: Mental Health Roles in the Implementation of Part H of PL 99-457, The Education of the Handicapped Act Amendments of 1986," An Issue Paper, Child and Adolescent Service System Program, National Institute of Mental Health, p. 3.

25. "The Role of Medicaid and EPSDT In Financing Early Intervention and Preschool Special Education Services," Report of Fox Health Policy Consultants, Inc., April 1990.

APPENDIX

DEFINITION OF SEVERE EMOTIONAL DISTURBANCE

A child with a severe emotional disturbance is one who, on the basis of a psychosis or other emotional/behavioral disorder, suffers from severe disability, which requires sustained treatment interventions for a year or more, and which generally requires attention from two or more agencies or professions.

A child meets the criteria for determination as having a severe emotional disturbance if all five (5) of the following are present:

A. Age:

17 years old or younger.

B. Diagnosis:

A primary diagnosis which meets DSM-III-R criteria of a mental disorder with onset in childhood or adolescence (excluding V-codes, adjustment disorders, mental retardation when no other mental disorder is present, or other forms of dementia based upon organic, physical, or alcohol/substance abuse disorders).

Although diagnosis alone cannot be used as a basis for defining long-term mental illness or severe emotional disturbance in children, certain diagnostic categories are most often associated with it. They include childhood schizophrenia, schizophrenia of adult-type manifesting in adolescence, pervasive developmental disorders, and other emotional/behavioral disorders which fulfill the disability and duration requirements of this definition, such as affective disorders and certain disorders with severe medical implications.

C. Disability:

The child must meet DSM-III-R Axis V criterion of severe functional impairment (a score of 40 or below on the GAF or Children's GAS) and experiencing significant limitations of major life activities in his/her capacity for living in a family or family equivalent and in two or more of the following areas (not to include impairment in functioning due to physical or environmental limitations):

1. self-care at an appropriate developmental level
2. receptive and expressive language
3. learning
4. social interaction and self-direction, including behavioral controls, decision making, judgment and value systems at an appropriate developmental level

Source: Illinois Department of Mental Health and Developmental Disabilities

D. Duration:

One year duration of the functional disability or, on the basis of diagnosis, at substantial risk of lasting more than one year.

E. Multi-agency need:

A child or adolescent with such a severe level of disability is most likely to have service needs and require intervention from mental health systems (public or private) and one of another child-caring services: health, special education, child welfare, or juvenile justice.

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