



Best Practice

Next Practice

Family-Centered Child Welfare

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Mental Health in Child Welfare
A focus on children and families

Mental Health Issues in the Child Welfare System

This issue of *Best Practice/Next Practice*, and the issue that follows, discusses the complexity of the challenges of mental well-being in child welfare. We focus on issues relating to mental health in child welfare, examining both barriers to and promising practices for accessible, appropriate care for all children in the child welfare system.

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A Young Child's Point of View on Foster Care and Adoption

So, are you wondering what I need? Are you wondering what I would do about all of this if I had the power?

First of all, it would help if you would start with one simple, clear commandment to yourself: Never forget that I am watching. Never forget that every single thing you do matters immensely to me (even when I work like crazy to make you think that it does not). And I will remember. You may be able to get away with treating me as if I am invisible for a while (perhaps long enough to "disrupt" me or move yourself to a different casework job). But in your heart of hearts you know I was there, watching. I was having deep feelings about what was happening to me and I needed someone to act if it mattered, hugely.

Second, don't imagine that I will ever stop yearning for my birth family (even though, as in other things, I will pretend otherwise). Help me find some way to keep a connection with them, even if I never see them again. Bring out pictures, or a life book, and hold me while I rage or sob or stare or all of these at once. And understand that none of this is a reflection on you. Don't

be surprised when I come back from a visit with them peeing in my pants or throwing tantrums in the bath that night. I told you: things matter to me. So I am going to have feelings about things that matter to me.

Third, it would help a lot if you would make the decisions that you need to make and stick with them. Some days I think my mind is going to explode because I know something is going on in my life but I can't tell what it is; later I'll learn that there was a court hearing that day and everybody in my life was wrought up and then it was "continued" (whatever that means, except mostly that nothing is getting decided and I still don't have a family). I don't get to make the decisions. You do. So have the courage to make them so that I can get a life.

Fourth, it would mean a lot to me if you would take good care of my foster family. They have their hands full. Sometimes they don't know what to do with me. So make sure someone is there to answer their questions, to encourage them, to help them understand me better. You won't like what will happen if I keep getting dis-

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rupted, and the only way I can think of to prevent that is to take extra care of the people that are taking care of me.

So have I told you anything that you wanted to know? Have I helped you understand how all of us feel who fell into this rabbit hole that is the world of foster care and adoption?

Adapted from Multiple Transitions: A young child's point of view on foster care and adoption

“Growing numbers of children are suffering needlessly because their emotional, behavioral, and developmental needs are not being met by those very institutions which were explicitly created to take care of them.” *Report of the Surgeon General's Conference on Children's Mental Health: a National Action Agenda.*

Many children in the child welfare system grow up in environments characterized by poverty, instability, or parents or caregivers with limited psychological well-being. The traumatic experience of abuse, neglect, and separation as well as environmental factors can lead to a variety of emotional problems for children and a greater likelihood of poor child well-being outcomes.

Results of a few research studies indicate that children in the child welfare system, especially those in foster care, represent a high-risk population for maladapt-

tive outcomes, including socio-emotional, behavioral, and psychiatric problems warranting mental health treatments. Foster care children represent an extremely high-risk population for mental health problems. Half of the children in foster care have adaptive functioning scores in the problematic range; among children ages 0 to 6, about 50 to 65 percent are in the problematic range in terms of developmental status. Among 2 to 27 year olds, about 50 to 60 percent have behavior problems, and among the 6 to 17 year olds, about 40 percent meet the criteria for any diagnosis with moderate impairment.

Children with emotional problems present challenges to child welfare staff. These children have more service needs and are in greater need of caseworkers' attention. Ever increasing caseloads, gaps in services and disparities in access, and little understanding of mental health problems in children make it difficult to meet these needs. Foster parents and relatives require services and caseworker time to deal with the challenges of parenting troubled children. The mental health problems of these children are not likely to disappear once they are adopted or reunified with their families. Therefore, children and parents need post-adoptive or post-reunification services to help them deal with lifelong effects of abuse, neglect, and separation.

In terms of mental health service use, children in the child welfare system use these services up to fifteen times more than other children in the Medicaid system. Foster children with behavioral problems are most likely to be seen. Data also show that children with a history of sexual abuse are three times more likely to receive mental health services, while children with a history of neglect are least likely to receive treatment. African-American and Hispanic children are least likely to receive services, and they need to display more pathology to be referred for mental health services. Developmental services are accessed significantly less than would be expected based on the high rate of developmental problems observed.

Resiliency and Vulnerability

There are many factors that can make a child vulnerable to the negative effects of abuse and neglect. Some children who grow up with seemingly so little have survived, healed, and recovered from much in their childhood. Other children who seem to have “everything” may be troubled, unproductive, and uninvolved later in life. There are several factors to consider.

First, there is seldom a simple cause-and-effect relationship in the ways children develop. Usually it depends on several other things in their lives. For example,

Disorders Usually First Diagnosed in Infancy, Childhood, or Adolescence

Recent evidence compiled by the World Health Organization indicates that by the year 2020, childhood neuropsychiatric disorders will rise proportionately by over 50 percent internationally to become one of the five most common causes of morbidity, mortality, and disability among children. The mental health problems affecting children and adolescents include the following:

Depressive Disorders

Depressive disorders, which include *major depressive disorder*, *dysthymic disorder*, and *bipolar disorder*, adversely affect mood, energy, interest, sleep, appetite, and overall functioning. In contrast to the normal emotional experiences of sadness, feelings of loss, or passing mood states, symptoms of depressive disorders are extreme and persistent and can interfere significantly with a young person's ability to function at home, at school, and with peers.

Major depressive disorder (major depression) is characterized by five or more of the following symptoms: persistent sad or irritable mood, loss of interest in activities once enjoyed, significant change in appetite or body weight, difficulty sleeping or oversleeping, psychomotor agitation or slowing, loss of energy, feelings of worthlessness or inappropriate guilt, difficulty concentrating, and recurrent thoughts of death or suicide.

Dysthymic disorder, a typically less severe but more chronic form of depression, is diagnosed when depressed mood persists for at least one year in children and is accompanied by at least two other

symptoms of depression (without meeting the criteria for major depression). Youth with dysthymic disorder are at risk for developing major depression.

Although *bipolar disorder* (manic-depressive illness) typically emerges in late adolescence or early adulthood, there is increasing evidence that this illness also can begin in childhood. Bipolar disorder beginning in childhood or early adolescence may be a different, possibly more severe form of the illness than older adolescent- and adult-onset bipolar disorder. Research has revealed that when the illness begins before or soon after puberty, it is often characterized by a continuous, rapid-cycling, irritable, and mixed manic and depressive symptom state that may co-occur with disruptive behavior disorders, particularly attention-deficit hyperactivity disorder or conduct disorder or may have features of these disorders as initial symptoms. Diagnosis and treatment of depressive disorders in children and adolescents are critical for enabling young people with these illnesses to live up to their full potential.

Anxiety Disorders

Anxiety disorders, as a group, are the most common mental illnesses that occur in children and adolescents. Researchers estimate that the prevalence of any anxiety disorder among children and adolescents in the U.S. is 13 percent in a six-month period.

Generalized Anxiety Disorder: characterized by persistent, exaggerated worry and tension over everyday events.

Obsessive-Compulsive Disorder (OCD) is characterized by intrusive, unwanted, repetitive thoughts and behaviors performed out of a feeling of urgent need.

Panic Disorder is characterized by feelings of extreme fear and dread that strike unexpectedly and repeatedly for no apparent reason, often accompanied by intense physical symptoms, such as chest pain, pounding heart, shortness of breath, dizziness, or abdominal distress.

Post-Traumatic Stress Disorder (PTSD) is a condition that can occur after exposure to a terrifying event, most often characterized by the repeated re-experience of the ordeal in the form of frightening, intrusive memories; brings on hypervigilance and deadening of normal emotions.

Phobias: social phobia—extreme fear of embarrassment or being scrutinized by others; *specific phobia*—excessive fear of an object or situation, such as dogs, heights, loud sounds, flying, costumed characters, enclosed spaces, etc.

Other disorders: separation anxiety—excessive anxiety concerning separation from the home or from those to whom the person is most attached; and *selective mutism*—persistent failure to speak in specific social situations.

ADHD

Attention deficit hyperactivity disorder (ADHD) affects an estimated four percent of children and adolescents in the U.S. in a six-month period. Its core symptoms

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include developmentally inappropriate levels of attention, concentration, activity, distractibility, and impulsivity. Children with ADHD usually have impaired functioning in peer relationships and multiple settings including home and school. Untreated ADHD also has been found to have long-term adverse effects on academic performance, vocational success, and social-emotional development.

Eating Disorders

Eating disorders involve serious disturbances in eating behavior, such as extreme and unhealthy reduction of food intake or severe overeating, as well as feelings of distress or extreme concern about body shape or weight. In the U.S., eating disorders are most common among adolescent girls and young adult women; only an estimated 5 to 15 percent of people with *anorexia nervosa* or *bulimia nervosa* and an estimated 35 percent of those with *binge-eating disorder* are male. Eating disorders often co-occur with other illnesses such as depression, substance abuse, and anxiety disorders. In addition, eating disorders are associated with a wide range of other health complications, including serious heart conditions and kidney failure, which may lead to death.

Eating disorders are not due to a failure of will or behavior; rather, they are real, treatable medical illnesses in which certain maladaptive patterns of eating take on a life of their own.

Autism and Other Pervasive Developmental Disorders

Autism and other pervasive developmental disorders (PDDs), including *Asperger's Disorder*, *Rett's Disorder*, *Childhood Disintegrative Disorder*, and *Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS)*, are brain disorders that occur in an estimated 2 to 6 per 1,000 American children. They typically affect the ability to communicate, to form relationships with others, and to respond appropriately to

the outside world. The signs of PDDs usually develop by 3 years of age. The symptoms and deficits associated with each PDD may vary among children. For example, while some individuals with autism function at a relatively high level, with speech and intelligence intact, others are developmentally delayed, do not speak, or have serious language difficulty.

Research has made it possible to identify earlier those children who show signs of developing a PDD and thus to initiate early intervention. While there is no single best treatment program for all children with PDDs, both psychosocial and pharmacological interventions can help improve their behavioral and cognitive functioning.

Schizophrenia

Schizophrenia is a chronic, severe, and disabling brain disorder that affects about one percent of the population during their lifetime. Symptoms include hallucinations, false beliefs, disordered thinking, and social withdrawal. Schizophrenia appears to be extremely rare in children; more typically, the illness emerges in late adolescence or early adulthood. However, research studies are revealing that various cognitive and social impairments may be evident early in children who later develop schizophrenia. These and other findings may lead to the development of preventive interventions for children. Only in this decade have researchers begun to make significant headway in understanding the origins of schizophrenia. In the emerging picture, genetic factors, which confer susceptibility to schizophrenia, appear to combine with other factors early in life to interfere with normal brain development. These developmental disturbances eventually appear as symptoms of schizophrenia many years later, typically during adolescence or young adulthood.

From NIMH Brief Notes on the Mental Health of Children and Adolescents available at www.nimh.nih.gov. For further information contact NIMH.

several years ago researchers were asked if children born with minor brain damage were more likely to become violent teenagers. Scientists found that if those children were growing up in well-functioning families and communities, they were no more likely than other children to end up as violent teenagers. If they were growing up in abusive families and dysfunctional communities, however, they were four times more likely to end up as violent teenagers.

Second, there is often an accumulation of risk and opportunity in a child's life. One event or circumstance does not lead to trouble in a child's life, but a combination of things can. These risk factors include low intelligence, poverty, absence of a parent, child abuse in the home, low educational level of parents, parental substance abuse, parental mental illness, and large family size. A child can grow up in a family where there are several of these risks and can deal with adversity. But research shows that children who grow up in situations where there are four or more risk factors can have significant troubles later.

As a complement to risk, there are opportunities, or assets, for children in their families, too. Assets are inside the child—their personality, their abilities, and their talents. Assets are also around the child—their family, their peers, in the school, and in the commu-

nity. The more of these opportunities that a child has the less likely that they will be troubled.

Third, we need to understand about a child's ability to cope and adapt to changes, called resilience. Being resilient allows a child to overcome difficulties in their life. What makes a child less resilient, less able to cope with problems or stress or become violent?

- Dealing with abuse and neglect at home
- Living in violent and impoverished communities
- Being between 13-15 years old (a critical age for many children)
- Being a boy. Boys are the most vulnerable.
- Facing issues of racism

Fourth, we need to understand temperament. Children have different attributes and personalities that color the way they deal with others. We need to learn how to work with or be parents to children with different temperaments.

Temperament does not doom children or guarantee their success, but it sets the probabilities and the terms of engagement. Some children who are most likely to develop into violent teenagers are temperamentally difficult or slow-to-warm children because they are children who, unless they are managed well, will gravitate to the negative behavior.

Fifth, we need to understand the need for spirituality. We need to understand and to help children understand that human beings are not simply animals with complicated brains, but are spiritual beings having a physical experience in life. Many children who are involved in spiritually promoting religious experience tend to be buffered.

Challenges

There are several barriers to providing mental health services to children in child welfare that include:



- Fragmentation of responsibility and funding
 - Gaps in services
 - Unmet need and disparities in access
 - Lack of family partnerships and support
 - Lack of workers' understanding of mental health problems of children and adolescents in the child welfare system
 - Lack of focus on screening, prevention, and early intervention
- Additional challenges in addressing and serving the mental health needs of children exist.

Access. Perhaps the greatest barrier to children receiving mental health care is access. This is especially true for low-income, minority families who are supposed to receive coverage under Medicaid in the child welfare system. The services are often unavailable, inaccessible, and inappropriate. Waiting lists are often very long.

Diagnosis. Another challenge is diagnosing mental health problems in children and youth. Abused or neglected children or youth with emotional problems are often looked at as acting up or being aggressive. In addition, case-workers and parents many times look to a doctor to medicate the problem away.

Assessment Practices. The lack of consistent assessment too often results in children not being identified as having mental health problems. Instead they are funneled into the special education

and juvenile justice systems—especially if the child is low-income and from minority background. Black youth, for example, are more likely to be referred for mental health services because of behavior problems they present rather than because someone identified warning signs that may have emerged much earlier. More often, they are sent to correction facilities because of these undiagnosed problems instead of receiving psychiatric treatment.

Recommendations

Screen children entering the child welfare system and link them with services when needed. Systematic procedures to identify mental health problems and treatment should be implemented for children entering child welfare where there is known to be a high prevalence of mental health disorders. Screening should be implemented upon entry into the system and periodically thereafter during the life of the case. When mental health needs are identified, children should be linked with appropriate services.

Focus on the needs of the early childhood population. Recent research highlights the importance of environmental factors in very young children in shaping brain development and subsequent behavior. This points to the importance of early identification and prompt intervention, as well as prevention, of mental health

problems of young children who are entering the child welfare system. This is especially important for children in foster care.

Coordinate services with other public and private services and supports. Child welfare staff should coordinate work with other systems to address other child and family needs, such as income assistance or health care, and incorporate services and supports from all necessary agencies and systems.

Children spend most of their day and receive most of their services through “educational” systems, such as child care centers, schools, and after-school programs. Therefore, it is important to educate the staff in these systems about the mental health needs of children in the child welfare system and to coordinate early intervention services.

Improve access to mental health services for children and their families. This includes providing services that are culturally sensitive, affordable, close by, and at accessible times for families.

Promote awareness in families and train staff working with children and adolescents for earlier recognition and appropriate identification of mental health disorders and referral to mental health services.

Attachment and Children's Mental Health

"Each stage in a child's life makes unique demands on the caregiver, and each stage brings with it a set of specific developmental needs and vulnerabilities. Because children are a part of a changing and developing system that includes their parents, caregivers, community members, extended families, and so on, they get into increasingly complex experiential realms as they grow and mature, and each of their reactions to a new experience is informed by those that have come before. For a young child whose attachments to significant adults are in a crucial stage of development, an abusive experience will have far different effects on him or her, and on the family, than will a similar incident when the child is ten or a teenager or a young adult." From *The First Three Years and Beyond: Brain Development and Social Policy*, 2002.

Attachment is important. It is the base upon which the emotional health, social relationships, and one's worldview are built. The ability to trust and form relationships will affect the emotional health, security, and safety of the child, as well as the child's development and future relationships. Normal attachment develops during the child's first two years of life. Problems with the parent-child relationship during this time, or breaks in the consistent caregiver-child relationship, prevent attachment from developing normally. A wide range of attachment problems may result in varying degrees of emotional disturbance in the child. The severity of this attachment disorder seems to result from the number of breaks in the bonding cycle and the extent of the child's emotional vulnerability and their resiliency. Therefore, interventions that attempt to promote high-quality caregiver-child relations and secure attachment patterns are effective in enhancing the resiliency of vulnerable children. Because attachment lies at the root of many emotional and mental disturbances, it is important to understand its significance.

Resiliency, Risk Factors, and Attachment

Resilience: An individual's competence and successful adaptation, or "bounce back," following exposure to significant adversity and stressful life events. Vulnerability is the susceptibility to negative developmental outcomes under high-risk conditions.

Risk and Protective Factors: Conditions that increase (risk factors) or decrease (protective factors) the likelihood that an individual or a family will later develop problems. Studies of resiliency in children have consistently found the most basic and important protective factor is a history of a caregiver-child attachment.

A child's emotional vulnerability can be affected by a variety of factors including genetic factors; prenatal development, including maternal drinking and drug abuse; prenatal nutrition and stress; Fetal Alcohol Syndrome and Fetal Alcohol Effect; temperament; and birth parent history of mental illness, such as schizophrenia or manic depressive illness. If an infant's needs are not met consistently in a loving, nurturing way, attachment will not occur normally.

The attachment-disordered child does whatever she feels like, with no regard for others. She is unable to feel remorse for wrongdoing, mainly because she is unable to internalize right and wrong. This child may be savvy enough to speak knowledgeably about standards and values, but cannot truly understand or believe what she is saying. The child may tell you that something is wrong, but that will not stop her from doing it.

Foster or adoptive parents need support in preparing for and dealing with attachment issues. For many children, the trauma causing this disorder occurred long before their involvement with foster or adoptive parents. The parents also need to know and understand that the child's behavior is not caused from their parenting, but from past traumas. From this base, new parenting interventions can be designed from a cooperative relationship to fit a child with special needs. While not all children in foster care or those who are adopted develop this disorder, parents need to be aware of this possibility. The child also needs to understand what force is driving his or her feelings and controlling the child's behavior.

A Cautionary Tale and Five Hard Lessons: Foster Families as Partners in Child Mental Health or “We have Alice...but it is Wonderland that really needs support.”

By Roger Friedman, Ph.D., LCSW

Why is it that foster families play minimal roles in the mental health treatment of foster children? In what ways do social workers and therapists contribute to this pattern of exclusion? Is it important to change the situation? Most professionals in child welfare recognize that foster parents are in a central position to know about and care for the foster child's emotional well-being. The mental health of children in foster care is closely linked to the relationships in the foster family, the birth family, and with all the providers that are supporting the placement. When a foster child has challenging psychological problems, like major depression, bipolar disorder, or serious anxiety reactions, the role of foster families as emotional stabilizers and mediators is critical. So why does mental health treatment of foster children remain such a medical, child-centered model? If foster parents were to be real partners in mental health treatment for their foster children, how would their behavior and roles change and what would social services need to do to support them? If a foster child is like Alice caught in a confusing and scary Wonderland, can a partnership with fos-

ter families and mental health providers help her find a way back home? This “Cautionary Tale” explores these important questions and offers some challenging recommendations for change.

Wonderland...we have a problem here!

Child welfare programs view foster parents and foster families as valuable child care resources, but usually not as partners in the process of helping children cope with major mental health issues. A variety of well-intentioned though unexamined reasons for this exist. First, when children enter foster care with serious emotional problems it is unlikely they have ever been assessed or treated for mental health issues. The lack of family-centered, in-home mental health services and the tendency of social workers to view child mental health problems through a medical lens leads to referrals that focus on the child's symptoms and ignore the potential strengths in a foster family. The child is the client, and the family is in the background. If the birth family is included in the assessment at all, it is defined in deficit terms as a toxic force. In this medical model, the foster family

may be relegated to the role of chauffeur, bringing the child to and from appointments. This approach to mental health problems places the professional in complete charge of goal setting and therapy. Foster parents are encouraged to look to the therapist to “fix” their foster child. Mental health experts reinforce this “fix it” approach by caring for the child client in a centripetal manner, that is, continuing to provide clinical services that only experts can deliver.

The stated goal of reducing symptoms in the child is well intentioned but foster families are excluded and disempowered from the treatment process. The sad result is that although children may get better temporarily, those who are caring daily for the child have little idea of how to maintain this higher functioning.

The needs of the foster family and their primary role in helping the foster child with his problems are usually ignored. Furthermore, the great challenge of how to find a permanent home, which may or may not include reunification with the birth family, may be overlooked. We have Alice in treatment, but Wonderland needs our support.

Foster parents contribute as well to this exclusionary approach to mental health services. They are often eager to turn over a difficult foster child to a mental health expert. Maybe the therapist can really fix the child since social services can not provide resources to help. This tendency to turn a child's care over to others comes from foster parents who often feel unskilled in approaching major mental health problems, are overwhelmed themselves with other foster children, and must balance these needs with the demands of their own biological children. Often one or both foster parents are working jobs that make the expected role of "chauffeur" feel like an intrusion rather than a real request for partnership. The cycle of foster parents looking to the therapist to cure their foster child and a helping system of professionals eager to take over the treatment of the child makes for a complementary pattern that is difficult to break.

Foster parents and therapeutic foster homes are scarce and precious resources for most child welfare programs. Out of concern that foster parents may leave the agency, social workers often hesitate to directly challenge foster parents to help with transportation or get involved in the treatment of foster children or be supportive to the birth family. Few in-home, family-centered resources are available to help a foster fam-

ily who is struggling with meeting competing demands.

When a foster child displays serious emotional problems, placements fail and children are moved to new homes because it is so difficult for even the most competent foster family and social worker to balance all of these challenges. Social workers are frustrated but have no alternative other than cooperating with the frustrated foster parent demand that a child be moved from their home because he is so "out of control" or so "bad." In truth, lack of family-centered supportive resources, a medical treatment model, and competing demands have overwhelmed the foster family. The foster parent is trying to be all things to all people; the social worker is trying to maintain some stability for the foster child. Sadly, however, the placed child has to deal with another rejection and reattachment process in a new foster care setting. Alice leaves home again, falling down a black hole into a Wonderland that feels increasingly unstable.

Can Alice ever find her way home?

At a theoretical level, child welfare professionals agree that the context of foster care is hazardous to everyone's health and needs to be changed. In a public health sense, foster care becomes iatrogenic for all involved, that is, the treatment

process itself makes the patient sicker. A whole new system of complex relationships is created each time a child is placed in a foster home. Even with the recent Adoption and Safe Families Act legislation that limits foster placement to fifteen months in most cases, many people still view the physical placement of a child to avoid maltreatment as the *end* of an intervention rather than just the *beginning* of services to the foster family. After the drama of the actual placement is over, a slow and labyrinthine process begins.

Stories abound of therapists who won't talk with case workers, case workers who know a placement is necessary but fear the reliability of foster care, foster families who are overwhelmed and then feel pushed around by case workers, birth families who are avoided at every turn by foster parents, and



foster children who long for, but cannot find, a stable home. Public mental health services do not exist in most parts of the country. Treatment resources have long waiting lists and brief therapy managed care contracts. Funding for much-needed in-home family-centered services has nearly dried up. The philosophical consensus to do something about this troubling resource and relationship complex does not often lead to systemic action. When change does occur it is due to a heroic foster parent or a social worker and the system itself is left intact.

The lack of follow through with ecological-based interventions for foster children is a reflection of a larger challenge inherent in collaborating across multiple systems of care. This complex arrangement makes matters all the worse for foster chil-



dren with major mental health problems, exacerbating symptoms and encouraging despair for the child and burnout for the helpers. Mental health, child welfare, and juvenile justice all have some conflicting goals and cultures and very separate delivery systems. Add to this the tensions that easily get created between a birth family and a foster family, and an ecologically minded therapist or social worker has a truly complicated scenario to address. It is very difficult and time consuming to collaborate among agencies, mediate the conflicts that arise, and shift the helping system to a more family-centered, ecological view of mental health service. One child at a time, a devoted worker or foster parent can make a difference, but the homeostasis in the system keeps patterns from really changing.

When faced with a large caseload and little time or energy to deal with these vast organizational dynamics, why not just talk with Alice for a while and ignore Wonderland?

Foster care placement of maltreated children began in the 1970s as an effort to temporarily protect a child from ongoing and serious abuse or neglect. It was a means to the end of a safer and permanent placement with the birth family or with relatives or significant adults in their community. Foster care was to be a part of a comprehensive strategy that supported changes in the birth family to the extent possible and linked the foster family as a resource to the birth family. The social worker's role was to mediate conflicts and facilitate these linkages. This idealistic view of foster care, however, has never been fully funded or realized by federal or state governments. For thirty years, the child pro-

tection system has been struggling with the consequences of this failure. The emergence in the 1980s and 1990s of foundation-supported family preservation, family team decision making, wraparound and family-to-family models of working with foster families/birth families demonstrated how systems of care can be constructively engaged. Nevertheless, these strategies require a political and financial commitment to system reform that is just not present in most localities and state governments. The spark of innovation and the policy/funding commitments to sustain model programs is rarely generated. Wonderland is the fragmented services context that everyone complains about in foster care, but very few have the energy and creativity to produce change.

Getting back home through Wonderland

If mental health treatment of foster children is to change and become more family-centered, it must begin with a new perspective about caring for placed children. This perspective must include the families that are caring for the children as well as the birth families. Foster families must become full partners in the child rearing and therapeutic care of children placed in their home. Birth parents should be supported in making whatever positive contributions they can to their child's life while in care. Where parental rights have been terminated, mental health treatment should seek to maintain active connections between the extended relatives and the child throughout the period of out-of-home care.

Social workers should facilitate team meetings where foster families and birth

families are involved in treatment planning, goal setting and therapy itself. Child welfare programs should offer support groups and in-home coaching and training for foster families in managing difficult mental health problems. Everyone must begin to behave differently and to think differently about the multiple sources of mental illness and the role of context in managing symptoms and relapses. More family-centered thinking and strength-based therapy is necessary. Families and professionals must take responsibility for Wonderland's condition and find ways to break down old barriers and to nurture collaboration. The following five lessons, learned over my years of foster care consultation and training, can help social workers, foster families, birth families, and therapists map out a more holistic approach to mental health services.

Lesson 1: Mental health care for children should be family-centered

Family-centered child welfare and mental health services must replace the traditional child-centered model of mental health treatment in foster care. The child must be protected, but the foster and birth parents are recognized as having a continuing place in the child's life and are accepted as equal partners in the treatment process. Foster families need help in learning how to look after foster children with mental health problems. The foster family's job is to emotionally stabilize an upset or depressed child and to avoid triggering serious reactions. With agency help, foster parents can mediate conflicts that often occur between foster children and their birth families. It is the

social worker's and therapist's responsibility to nurture and coach foster families in learning how to more successfully manage troubled foster children and at the same time meet the demands of their own family members. The physical placement of a child to avoid maltreatment is the beginning of support to the foster and birth family and not the end.

Lesson 2: Foster families and providers must be partners

Never do anything for the child without the child, the family, and other providers present. Family-child-professional teams must become commonplace. These teams, which include the foster family, birth family or relatives, foster care social worker, and therapist, review mental health assessment and help to set goals and plans for treatment.

The treatment plan is individualized for the child, and roles for everyone on the team are identified. The team meets periodically to determine if desired outcomes are achieved, and if not, what can be done differently. The foster and birth parents/relatives need to feel ownership of the plan, and this usually involves them having considerable input in describing desired outcomes for the treatment. What is important to the families involved? What changes do they want to see in the foster child's behavior? What help

do they want as families? How will they know these changes have occurred? For example, set up a scale from 1 to 10 with the child and family and see where the child's behavior is now and what will be different at number 8? Well-formed treatment goals are small, important to the child and family, described in concrete terms, realistic, and perceived by the child as challenging but doable.

Lesson 3: Foster families are frontline therapists

Mental health treatment for foster children should actively involve the families of the child in the treatment process. This involvement can include regular or periodic family therapy meetings as well as family education about how to manage and respond to symptoms or outbursts that occur at home. The focus of treatment is not for the therapist to "fix" the child and return him to the foster family, but rather to help the child and all those who care for him be supportive and responsive to his needs. Some guidelines for foster families are provided on page 14.

Lesson 4: Support the whole foster family

Everyone in the foster family plays a role in making the placement successful. Often another child in the home may have a more important role in maintaining a foster child's well-being than the foster

parent. All the members of a foster family should be included in support groups that meet at times they can fit into their schedule. Therapists or social workers should be available to meet as coaches with everyone in the family to talk about the impact of fostering a child and how to manage this constructively. Issues of favoritism among children and how to meet the needs of their own biological children are rarely addressed openly with foster parents and should be part of a supportive dialogue. During particularly difficult periods for the foster family, respite care for the foster child should be available.

Even brief flexible hospitalizations have a place in a continuum of services; a foster child who may become out of control can enter in-patient care and then easily return to the foster family with follow-up from the hospital staff. In-home coaches or support services should also be available during particularly difficult times of day, such as from after-school through dinner/homework time, or in the morning getting ready to go to school. The most important message of this lesson is that foster families need as much support in the community and home as do birth families. To ignore or minimize the pressures of foster parenting puts the placement and the foster child with emotional problems at great risk.



Lesson 5: Foster and birth families should stay connected

The greatest psychological challenge for most foster children is balancing their desire to be loved and accepted by both their foster and their birth families. This is a difficult and very “political” task for a child, and especially when depression or severe anxieties accentuate a sense of loneliness and being unloved. Foster parents must try to be supportive and respectful of the birth family and communicate this to the foster child. Suggestions for helping relatives remain connected throughout the placement include:

- Talk openly with the child about the birth family.
- Talk openly with the birth family about the child and his/her problems.

- Normalize and accept feelings the child will have about their family.
- Discuss medication and treatment strategies with the birth family or relatives.
- Request a photo of child’s family to display in the foster home.
- Arrange sibling visits in the foster home.
- Ask the birth family for advice when the child is very depressed or anxious.
- Exchange letters with child’s family.
- Encourage birth parents or relatives progress.
- Have a positive view of the birth family and communicate this openly.
- Mentor or support birth family members.
- Give positive progress reports to relatives in the foster child’s presence.

- Welcome the child’s parents or siblings into the foster home.
 - Continually support birth family or relatives after reunification.
- If a foster child is like Alice in Wonderland, the challenge for social workers, case managers, therapists, and foster families is clear. Alice cannot be treated for serious mental health problems in isolation of Wonderland. A family-centered approach to mental health treatment is required, and foster families need to become full partners in treatment. This is a major change in how foster care systems operate. It is the only way to get Alice safely home.

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Guidelines for foster parents in supporting foster children

- Reduce the level of expressed emotion in the house for foster children with major depression or bipolar disorder. Anger, worry, and love should all be expressed with less emotional intensity—children with major mood disorders benefit from a family environment that is able to turn the emotional volume down in their personal conversations with that youngster.
- Anger and unresolved conflicts usually trigger episodes when there are major mood disorders and anxiety disorders in children. It is especially important for the foster family to calmly and quickly solve conflicts and reassure the foster child that the current disagreement will work out.
- Everyone in the foster family, including siblings and other foster children, should be brought into discussions about helping each other and being aware of the needs of a youngster dealing with a major psychological disorder. A good way to say this is that everyone in the family has something hard they are working on and need help with in their lives—in our family we all support each other and never make fun of anyone's personal issues.
- Help a foster child make a chart of when anxiety or depression is at its worst and then list a few simple activities that can help the child gain control over these negative feelings. Activities can include talking positively to himself, reaching out for help from a friend or foster parent, distracting oneself with a fun activity like TV or sports, taking a bath, writing in a journal, playing some favorite music, deep breathing, or exercising. Ask the child to identify how other family members can help them cope better with the symptoms when they get overwhelming. The important message is that the foster parent helps the child to gradually take responsibility for his or her own symptom management.
- Taking medications as prescribed may be an important part of the treatment process for some disorders. Foster parents should help a child remember when and how much to take as well be aware of when a prescription needs to be renewed. If foster parents notice any negative effects or feel that the medication is not helping, they should contact the therapist or psychiatrist directly.
- Sleep cycles are important for mood and anxiety disorders. Sleep disruption or deprivation contributes a great deal to feeling depressed and anxious. Foster children with major mood disorders should have regular bedtimes and get from 8 to 10 hours of sleep at night, depending on the age of the child. Staying up late for many nights, even if it is a fun activity, means lost sleep and this makes a vulnerable child even more at risk.
- Separate the illness from the child. Many foster families and professionals see a child with a major diagnosis like depression as sick and therefore in need of protection. It is wiser to externalize the diagnosis by talking with the child about the "illness" as something they all are fighting together—"we're going to fight that depression together and keep it away from you," or "feeling so afraid right now about school is just your depression speaking to you—let's ignore it by focusing on something good you will do today." This strategy empowers children and family members to support each other and normalizes the person who is experiencing the difficult symptoms.
- Hopefulness and self-confidence are the keys to resilience. Resilience is what children need most. Regardless of the difficulty of symptoms or the pain a child is experiencing, foster parents need to communicate a sense of hope about the future and confidence that working together they can all make a difference. Family life is never without problems, and the challenge for everyone is how to be resilient or roll with the punches that life brings. This kind of reassurance and life philosophy needs to be a part of every foster family's message.

The Mental Health Service Array

Supports and Services Needed To Support Children and Youth in the Child Welfare System

Results of the Child and Family Services Reviews indicate that most states do not have an adequate mental health service array for children and youth in the child welfare system. Most public mental health care system resources are limited, which impacts on accessibility to care, the types of services available, and the length of treatment provided. In addition, managed care systems in the private and public sectors have changed the types of services and the number of sessions available to clients. As a result, child welfare workers find that referrals and services to meet the mental health needs of their families can be quite challenging. Long waiting lists, a shortage of bicultural/bilingual services or few professionals that accept Medicaid payments are common problems.

The following is the full array of mental health services for children and youth—including prevention/early intervention services, home-based services, and out-of-home services needed to support children and families who enter the child welfare system. While no jurisdiction currently has all of these services available, here is a “wish list” of what an optimal array of services would include to fully support children, youth, and their families.

Community/Neighborhood Prevention/Early Intervention Services:

- *Community Services Information and Referral.* All jurisdictions need a center and/or a staffed telephone line where community residents can find out about existing services and programs that address children’s mental health needs, and the procedures and requirements for receiving them.
- *Crisis Stabilization Services.* Some jurisdictions may need to develop services for families in crisis—who are at imminent risk of child maltreatment because of a child’s mental health issues—to return them to pre-crisis functioning. These can include 24-hour services used for short-term emergencies.
- *Primary Child Health Care.* Primary and basic health care services for children are needed to treat, prevent, and detect physical and mental disorders and to enhance children’s physical and psychosocial well-being. Medicaid’s Early Periodic Screening, Diagnosis, and Treatment (EPSDT) is a primary child health care service available to qualifying children that can be used to detect, early on, emerging mental health issues and developmental delays that place children at risk.
- *Home Visits to Parents with Newborns.* This service promotes positive parenting and child health and mental health development, thereby preventing child abuse, neglect, and other poor childhood outcomes. The largest home visiting program in the United States, Healthy Families America, is sponsored by Prevent Child Abuse America (PCA America).
- *Head Start/Early Childhood Education.* These programs can be very beneficial to

children with emerging mental health needs because of their emphasis on psycho-social development.

- *Mentoring for Children and Youth.* The provision of an adult to mentor a child or youth who is experiencing mental health problems can be very beneficial, particularly for children from a single-parent home. Big Brothers/Big Sisters is one such mentoring program; mentors, who work under professional supervision, provide individual guidance and companionship to boys and girls deprived of a parent.

Home-Based Services

- *Wrap-Around Services.* Some jurisdictions have funds for wrap-around services for children with mental health issues that allow them to provide flexible and “whatever is needed” services.
- *Behavioral Aides.* Professional or paraprofessional aides who provide in-home services to parents who are having difficulties managing the behavior of their child to teach and mentor more effective behavioral discipline or management skills—can be an essential service for families with children who have mental health issues. These aides may also work with the child.
- *Outpatient Mental Health Services.* Community-based counseling and other mental health services that do not require institution-

alization are essential for families with children who have mental health issues. Services may include evaluation/assessment, counseling (family/marital, individual, peer, crisis counseling), and pharmacological management.

- *Child/Adolescent Day Treatment.* Almost every jurisdiction needs community-based mental health services for children and adolescents with mental health problems to prevent institutional placement. This service is sometimes known as “day school.”
- *Sexual Abuse Treatment.* Treatment services for children, their families, and adults who are child sexual abuse survivors are essential mental health services.
- *Therapeutic Child Care.* Most jurisdictions will need to make available child care that is provided in a therapeutic milieu because of the emotional needs of the child.
- *Intensive Family Preservation Services.* Intensive in-home clinical and other services are often needed by families whose children have mental health issues. Services are designed to assist in the preservation of families—including adoptive and extended families whose children have either experienced or are at risk for parental abuse or neglect, or are in crisis and are at imminent risk for removal from their homes. Some jurisdictions have implemented Multi-Systemic Therapy (MST) which has been

proven to be effective in working with youth in the juvenile justice system and their families.

Out-of-Home Services

- *Treatment Foster Care.* Most jurisdictions will need to make available specialized care provided by foster families, who usually have had special training, for children removed from their homes because of maltreatment and who have heightened mental health needs.
- *Residential Programs for Adolescent Behavior Problems.* This service—placement of an adolescent who has been removed from his/her home into a residential program because the youth’s behavior problems require specialized care that would not be feasible in foster care—is an increasingly needed resource in many jurisdictions. One example is wilderness programs.
- *Residential Adolescent Substance Abuse Treatment.* Because of the increase in adolescent substance abuse, most jurisdictions need to have this service available.
- *Inpatient Child/Adolescent Mental Health Treatment.* Most jurisdictions also need this service for children and adolescents in acute psychiatric crisis until they can be stabilized and moved into a less-restrictive placement.

Creating Effective Systems for Mental Health Care and Services

By Jan McCarthy

“Among the 2001 and 2000 CFSR reviews, only one state had the mental health item rated as a strength. In 2002, we found the most common concerns to be in the scarcity of mental health services, the questionable quality of mental health services, and the lack of mental health assessments of children even when there was adequate reason to conduct such an assessment.” —Linda Mitchell, federal review team for the Child and Family Services Review, Children’s Bureau, January 2003.

Need for Services— Children and Families

Children come to the attention of the child welfare system for many different reasons. Many have experienced abuse or neglect, and someone has determined that they need protection. In other families, parents have turned to the child welfare system as a last resort to gain access to extensive mental health services for their children that have been unavailable through other child-serving systems. Children in both of these groups tend to be extremely vulnerable and are at high risk for health, mental health, and developmental problems. For children placed in foster care, the trauma of separation from their families and the experience of multiple moves within the foster care system itself increase their vulnerability and compound their mental health problems. Many parents, who experience the multiple stresses that lead to involvement with the child welfare system, also need mental health services and supports as well as substance abuse services.

Challenges

Just knowing that children and their families have significant mental health needs does not lead to meaningful, responsive,

high-quality child mental health services. States and communities throughout the country must overcome significant challenges— within the child welfare system itself, within the mental health system, and across systems. Some of these challenges are identified below.

The child welfare system is challenged with:

- Identifying the mental health needs of children as they enter the system
- Instituting policies that require mental health assessments
- Understanding the mental health issues that children face
- Providing follow-up services when mental health needs are identified
- Documenting services that are provided
- Providing support and sharing information with all caretakers

The mental health system is challenged with:

- An inadequate array of community mental health services for children
- A lack of qualified providers who have knowledge of the child welfare system and the special problems faced by many families

- Low reimbursement rates for providers leading to an unwillingness to serve families on Medicaid
- Limited services that are culturally and linguistically appropriate
- Individual, rather than family-focused, services
- Restrictive management mechanisms in many managed care plans
- Time-limited services and placements
- Waiting lists

Cross-system challenges include:

- Communication issues
- Confidentiality issues
- Information systems that do not “talk” with each other
- Overlapping roles among child welfare workers and care managers
- Court systems involvement
- Budget crises
- Inflexible funding sources
- Cross-system training

Trends

The Georgetown University Center for Child and Human Development and other partners, including the Child Welfare League of America, have conducted studies to track health care reforms. Their focus has been on how managed care impacts children and families with behavioral health needs. Georgetown has also completed a study that identifies and describes promising approaches for meeting the health, mental health, and developmental needs of children in the foster care system. These studies have led to similar findings about mental health services for children and families in the child welfare system.

Some child welfare systems have essentially become the children’s mental health system. Seventy-two percent of the respondents to the 2003 State Survey of Health Care Reform Tracking Project reported that the child welfare system has access to Medicaid funds for behavioral health services *outside* of the reform. Most of these respondents (83 percent) stated that the child welfare system is responsible for providing extended care services (that are not offered within managed care). The same survey noted that services regularly used by child welfare systems are among those least likely to be included in managed care, e.g., respite care, therapeutic group care, residential treatment, behavioral aide services, and crisis residential services. Therapeutic foster care is included in 60 percent. In a national study conducted by the Child Welfare League of America (CWLA) in 2000, more than half of the respondents reported that parents in their states relinquish custody to access mental health services for their children through the child welfare system. The respondents, however, could not say how frequently this happens.

Very little aggregate data exists about the mental health needs of children in child welfare. In the CWLA study mentioned above, less than 40 percent of the respondents reported a capacity to determine the percentage of children in child welfare who have serious mental health needs. Less than a third were able to say whether parental mental health and substance abuse problems were the primary reasons for a child’s placement.

Partnering successfully with families continues to challenge child welfare systems. Although nearly 70 percent of chil-



dren in foster care eventually return to their birth parents or to relatives, the study of promising approaches for meeting the health care needs found that many sites did *not* systematically include a child's birth parents or relatives in health care planning. Frequently, there was no policy about including birth families in the health and mental health care of their children. Instead, decisions about involving families were left to individual social workers. Some respondents identified practices that actually excluded participation by birth parents, e.g., holding clinical team meetings to review multidisciplinary assessments without birth parents present (social workers notify parents of the findings after the meeting). Such practices seem counter to the first well-being outcome in the Child and Family Services Review—"families have enhanced capacity to provide for their children's needs." However, there is good

news from one of the studies. Interviews with families from the child welfare system reveal that some interagency initiatives, created to meet the needs of children with serious emotional disorders, are engaging families more positively. Families felt that the social workers, care managers, and the child/family team really *listened* to them and offered treatment based on what the families knew would work for their children. They felt they had a say and were not just being told what to do. They also described a focus on the *whole* family, rather than only the child with identified mental health needs.

Improving access to health and mental health care enhances a child's chance for permanency. Some of the benefits described by respondents in the study on meeting health care needs were directly linked to the three major goals of the child welfare system—safety, permanency, and

well-being. Comprehensive mental health care enhances a child's chance for healthy development, reduces stress for caregivers, stabilizes placements, and provides the services families need to care for their children. Having adequate information about a child's mental health enables parents, agencies, and courts to make recommendations for appropriate placements. Whether the goal is reunification or another permanent placement, children benefit from appropriate services, and parents benefit from education and support services related to their children's care.

Working together to solve problems related to mental health issues has improved interagency coordination and collaboration. About two-thirds of the respondents in the 2003 State Survey of the HCRTTP reported improved interagency coordination as a result of the managed care reforms. Many respondents in the study on meeting the health care needs felt that working together helps different systems become focused on the same goals for children and families. They also described the benefits for both systems in locating mental health staff in child welfare agencies. The Child and Family Services Review (CFSR) process provides an opportunity for states, communities, child-serving agencies, and families to work collaboratively on state self-assessments, on-site reviews, and in developing program improvement plans.

Systems of care demonstrate strong collaboration and provide positive results for many families and children in the child welfare system, but on-site reviews by CFSR teams find that in some communities systems of care have not yet

translated into statewide reform. A recent analysis of 2,220 youth from 43 communities that receive federal funds to develop systems of care for children with serious emotional and behavior disorders presents interesting findings about children in foster care. Approximately 26 percent of the children in this analysis were in foster care; 74 percent were not. Children in foster care show greater risk factors in their histories:

- More previous psychiatric hospitalizations
- More often victims of physical or sexual abuse
- Have run away more frequently
- Have abused substances more
- Are more likely to have been sexually abusive

Family histories of children in foster care show that their parents have higher rates of:

- Psychiatric hospitalization
- Family violence
- Criminal convictions
- Substance abuse

Families involved with child welfare also received treatment for substance abuse at a greater rate. Children in foster care showed greater *use* of services such as crisis stabilization, individual therapy, group therapy, recreational activities, respite care, inpatient hospitalization (during the first six months of service), and therapeutic group homes than other children in systems of care. Despite differences in histories and some differences in diagnoses and service use, children in foster care show success and improvements at 6-month and 12-month intervals at a rate comparable to children not in foster care.

Building Systems of Care

While progress has been made, many communities throughout the country lack well-developed systems of care. The challenge for states and communities is to accomplish broad system reform that applies the values and principles inherent in systems of care statewide and across all child-serving systems, and to do this collaboratively.

Child welfare systems have choices in how they try to meet the mental health needs of children and their families. The child welfare system can become the mental health system for children by providing or purchasing mental health services with child welfare funds and Medicaid funds allocated to the child welfare system budget. While this may offer a short-term solution, it saddles the child welfare system with the *full* responsibility for the mental health care of children who are in the system due to abuse or neglect. It also can force parents to go to the child welfare system to find mental health services for their children. This solution can cause children to be sent away to get services. It does not build on the strengths of the child welfare and mental health systems. It does not strengthen the ability of communities to provide community-based mental health services for families and children.

Another choice is for multiple child-serving systems to work together, with families as partners, to create a stronger and more comprehensive community-based mental health system for children and families. In this approach, key partners come together to plan for and deliver these services, families are full partners, and cultural competence in service delivery is essential.

Conclusion

Collaboration is at the heart of system building. Working together, agencies and families can conceptualize a vision, agree upon basic values to guide the system that is being created, identify service gaps, set common goals, blend funding streams, offer incentives to providers, develop cross-system training for providers, co-locate staff from mental health and child welfare, and much more. This approach builds on each agency's strengths and shares responsibility throughout the community.

Notes

This article is based on a summary of findings from studies conducted at Georgetown University and on the author's own experiences in working in child welfare systems, mental health systems, and systems of care. For a complete list of references and links for this article, see our .

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Helping the Invisible Children

Supporting parents with mental illness and their children

Alison and Fred are parents of Sarah who is eight years old. Alison and Fred both have a history of psychiatric problems. Alison is diagnosed with Schizoaffective Disorder and Borderline Personality Disorder. She has attempted suicide several times and has been hospitalized numerous times. Fred is diagnosed with Personality Disorder, Not Otherwise Specific, and Mental Retardation. Fred and Allison have periods of violent arguments.

Sarah has a seizure disorder and a serious emotional disturbance. Child Protective Services (CPS) became involved in the family due to repeated concerns of abuse and neglect. CPS also had concerns about Alison's poor mental health status and its effect on her parenting ability. Specifically they identified poor nutrition, poor hygiene, and the inability to manage Sarah's behavior and mental health issues. Sarah was placed in foster care and a termination of parental rights was initiated. At the same time, Alison had developed a reputation with CPS for being demanding, difficult, and disrespectful. These attitudes compromised her mental health treatment as well as interfered with creating a working relationship with CPS.

Surely it seemed that Alison and Fred would lose their parental rights.

Alison's and Fred's mental health case manager referred them to the Invisible Children's Project (ICP). Together, with their ICP case manager, Alison and Fred established their central goal: reunification with Sarah. As a cornerstone to this plan, they decided that ICP would mediate their relationship with CPS and that Alison and Fred would learn more effective strategies to work with CPS. CPS requirements for family reunification were integrated into Alison's and Fred's ICP service plan. ICP focused on arranging and supporting their consistent mental health treatment and medication management. To do this ICP scheduled and attended all medical and mental health appointments with them. Often the case manager facilitated communication between them and their providers and ensured follow through with treatment. Home visits provided parent education and monitoring of Fred's and Alison's progress. These visits also focused on developing their understanding of general child development, behavior management strategies, and the importance of Sarah's school attendance.

Today, both CPS and ICP case managers say that many of the family's goals have been met. ICP

developed a good working relationship with CPS that enabled CPS to continue to provide services to the family and to be willing to develop a reunification plan. Alison's and Fred's mental health is well coordinated; they regularly attend appointments and have a good relationship with their providers. Alison has not needed any hospitalization. ICP helped arrange for adequate housing and continues to work with Alison and Fred at home on parenting issues. With the help of ICP and their assurance that ICP would provide home monitoring and supervision, Sarah was returned home. Sarah's school attendance, once a significant problem, is now excellent. Both parents admit that parenting is hard and that managing Sarah is difficult, but they are trying very hard. Alison's most significant progress is recognizing when she needs help and to ask for help from an appropriate source.

What made the difference in the family's case? CPS workers, who have worked with Alison and Fred for more than ten years, state that Sarah would not be home without ICP's involvement. ICP provided the accessibility and availability that CPS could not. Also, a tightly coordinated array of services and su-

pervision were critical to Sarah being returned home.

Often service systems view adults with mental illness or co-occurring disorders in isolation of their children, and do not provide comprehensive, integrated services that could enhance family stability. To service providers, the children of parents with mental illness, like Sarah, are “invisible children.” Their unmet service needs can lead to further family instability and disruption.

How Mental Illness Affects Families

Parents with mental illness face many challenges from dealing with reproductive issues to custody loss and past and present victimization, often without family support due to the lack of services and specialized programs. Family life can be deeply affected, and children can be confused about their roles, as they often assume many adult responsibilities. Children living with a parent with serious mental illness are also adversely affected by the poverty that often accompanies the illness.

Children who have parents with mental illness may be quite vulnerable to being placed in foster care, like Sarah. Some studies report that as many as 70 percent of parents with mental illness have lost custody of their children. Some state laws cite mental illness as a condition that can lead to loss of

custody or parental rights. Many people believe that those who need mental health services are naturally unfit as parents, or that parents with mental illness are violent and are an increased risk for abusing their children. As a result of these beliefs, many families do not seek help, fearing they will be judged as unfit parents, yet without treatment or services, their parenting capacity is diminished.

Filling the Void: The Invisible Children’s Project

Millions of adults in the United States are affected by mental illness. The majority of these adults are, or will become, parents. Despite the prevalence of parenthood among adults with mental illness, and the potential for negative effects on some children, few programs or services are available to meet the needs of the parents and their children. In addition, available services have not been evaluated; little is known about what is helpful for families or effective to enhance family and family member functioning as well as quality of life.

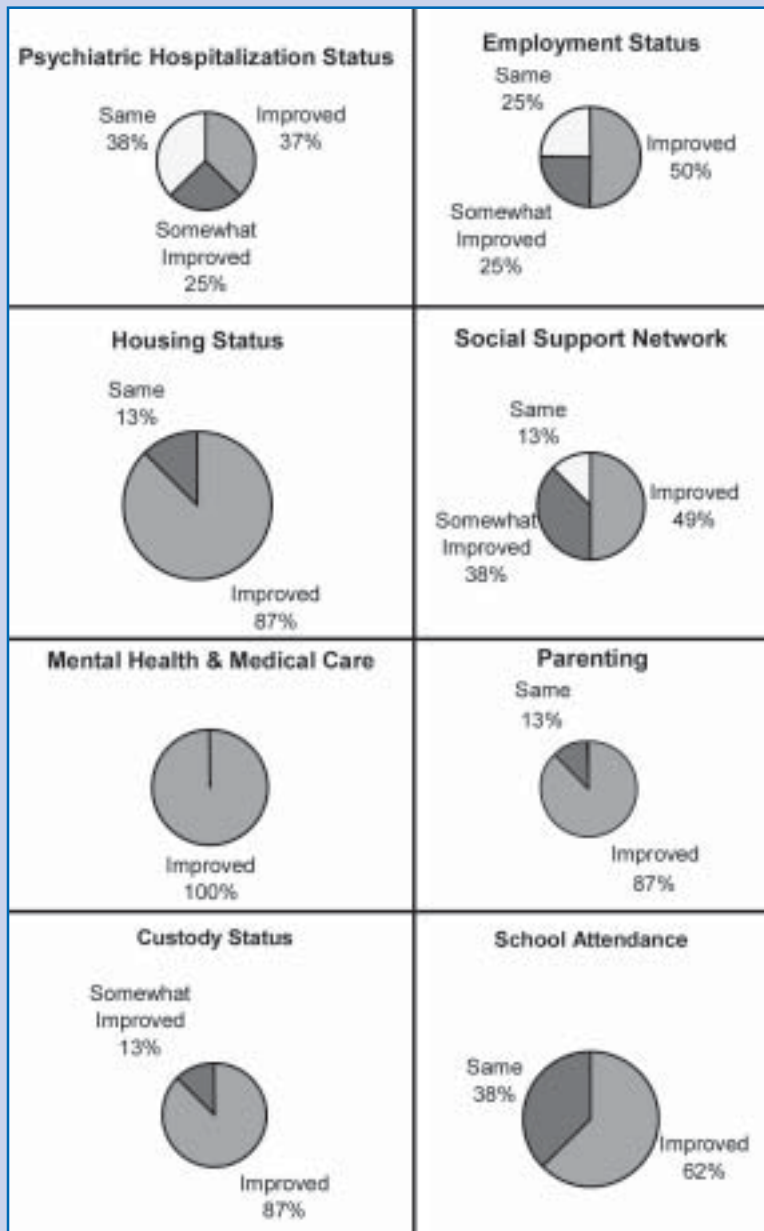
In 1991, under the leadership of Lucinda Sloan Mallen, whose own childhood experience was that as an “invisible child,” the Mental Health Association in Orange County, Inc., Goshen, New York, embarked on a deliberate plan to raise awareness of the issues that families face when par-

ents have mental illness. Her advocacy influenced policy makers at the local, state, and national levels resulting in systemic change and the development of the model program, the Invisible Children’s Project (ICP). This family-centered, strengths-based, and comprehensive program has made significant impact on the lives of parents diagnosed with a mental illness and their children. (See box next page.)

This program represents best practices in terms of advocacy, consumer involvement in both design and delivery of service, cross systems cooperation, and dissemination of information through training throughout the country. ICP supports parents who have a diagnosis of a mental illness in their efforts to be the best parent possible and to keep the family unit together. To do this ICP provides home-based, family-centered case management services.

Supporting Parents and Children

The program is founded on the assumption that mental illness does not preclude good parenting, and that all parents want to be the best parents they can be. The family rather than the individual is the unit of service. ICP emphasizes access to and coordination of multiple services to support the safety and functioning of all family members for as long as necessary.



Parents with mental illness and their children who received family-centered case management services through the Invisible Children’s Project (ICP) showed improvement across eight multiple outcomes. These included hospitalization, employment, housing, medical and mental health care, custody, employment, social support, parenting, and school attendance. CPS workers stated that children were returned home or maintained in the home as a direct result of ICP involvement. While service costs increased for some families, benefits were great. Parent and agency goals were achieved, and more expensive, disruptive, and potentially damaging out-of-home placements, e.g., hospitalization and residential care or foster care, were avoided.

From the Invisible Children’s Project: A Family-Centered Intervention for Parents, p. iii.

The program empowers parents and gives them the necessary support to create a safe and nurturing environment for their children. Many of the parents also seek assistance with preventing out-of-

home placements for their children. Other parents seek custody of children who have been “lost,” or placed in foster care. The program includes family case management with 24-hour access; support for

housing; respite child care; planning in the event of parental hospitalization; advocacy with schools; social services; family court; parenting training; vocational training; educational support; in-home

clinical services; information; referrals; linkages to the community; budget counseling and recreational family activities. The program also offers parents support and education during and after a pregnancy, provides a variety of therapeutic and recreational activities for children; and supports special classes or items for children and their families.

Many families who work with the Invisible Children's Project are at risk for having their children placed in foster care. This concern often supersedes all other issues in a parent's mind. To prevent out-of-home placement, it is important to understand the nature of risk to which children may be subjected. "Child outcomes appear to be related to many variables, alone or in combination with a parent's mental illness" (Nicholson, 2000). In other words, a parental mental illness is a risk factor that may lead to foster care placement for a child. However, often there are multiple risk factors occurring when a family enters the Invisible Children's Project. These risk factors may be, but are not limited to, role reversal with the parent, increased health problems, withdrawal and isolation, problems in school, and shameful feelings about family. Once these factors are identified in a given family, case managers work to resolve concerns individually and as they occur. Often by doing this the stress level of the entire family is reduced, which has positive con-

sequences for the parent with the mental illness. The Invisible Children's Project provides the support and links to community resources to help reduce risk and therefore increase the chances for the parent and family's success.

Measuring Success

Since 1993, the Invisible Children's Project has served more than 500 men, women, and children. Families entering the program are often homeless, poor, and without support systems, yet many of the families in the program have moved into independent living situations and home ownership. Employment, education, self-sufficiency, family unification, and the development of natural support systems increase. There is a decrease in hospitalizations and a decline in the number of children removed from the home. This outcome has obvious tremendous emotional value in the lives of family members as well as economic savings for the community. One parent in the program states, "Therapy and medication played a part in my recovery, but the Invisible Children's Project is a miraculous gift from God, which is directly responsible for giving me and my children our lives back."

Training Others

In addition, in partnership with the National Mental Health Association and the Mental Health Association in New York State, ICP

offers training and technical assistance to develop similar programs. As a result of this collaborative work, the Invisible Children's Project core program principles are being replicated across the country. Seven states have begun the process of creating systems change, task force development, coalition building, and are developing programs to work with the entire family when a parent has a mental illness. A training manual *Working With Parents With Psychiatric Disabilities and Their Children: A Family-Centered Approach*, written by the Mental Health Association in Orange County, is disseminated by the Mental Health Association in New York State.

Notes

Nicholson, J. (2000). National Mental Health Association Public Education Training Conference. New Orleans, Louisiana.

Reference: http://www.mhanys.org/ebpdb/spotlight_icp_report.pdf

For more information about The Invisible Children's Project, contact Mental Health Association of Orange County, 20 Walker Street, Goshen, NY 10924; 845.294.7411, mha@mhaorgeny.com; also visit www.nmha.org.

The Color of Mental Health in Child Welfare

“The court process was found to play a significant role in referring children to services. Significant differences by race and ethnicity were found in mental health service utilization prior to the child’s protective placement, as well as service orders and post-placement service use.

Caucasian youth were more likely to receive orders for psychotherapy and to have documented use of psychotherapy than were African American and Hispanic youth, even when the possible confounding effects of age and type of maltreatment were controlled.

Caucasian youth were more likely to enter the system with a history of counseling and to receive counseling during the first eight months of out-of-home care. Although no statistically significant racial/ethnic differences of frequencies of other types of service use were found, there were higher rates of use by Caucasians on almost every type of service use prior to and post-removal from the home.”—Garland, Ann F. and Besinger, Bridgett A. (1997). Racial/Ethnic differences in court referred pathways to mental health services for children in foster care. *Children and Youth Services Review*, 19, 651-666.

The Need for Mental Health Services

One of every five children and adolescents in the general United States population has a mental disorder, which, if left untreated, is often debilitating. Effective treatments exist for many types of mental health disorders, such as attention deficit hyperactivity disorder, conduct disorder, mood disorders, and anxiety disorders. Yet most children and adolescents who need a mental health evaluation and/or services do not get them. For example, in a 12-month period, 2 to 3 percent of children ages 3 to 5 and adolescents 6 to 17 used mental health services. Of children and adolescents between the ages 6 and 17 who were defined as needing mental health services, nearly 80 percent *did not* receive mental health care. This trend is more pronounced for Latinos and

the uninsured. Mental health services are seldom used among preschool children.

Most public and private human service systems do not appropriately serve children and families from racial and ethnic minorities. This results in increased rates of infant mortality; learning, emotional, and physical disabilities; school drop-out; and teenage pregnancy. In addition, minority populations are also more likely to enter the child welfare system, be placed out of their homes and communities, be incarcerated in youth detention facilities, and be “rehabilitated” into adult correctional systems. These racial/ethnic disparities are important because entry into child welfare may represent an important “gateway” into rehabilitative and supportive services, such as mental health services.

Disparities in the Use of Mental Health Services

Many factors are related to the use of mental health services, for example, the child’s age (older: *higher use*), gender (male: *higher use*), type of abuse (sexual and physical abuse: *higher use*), severity of emotional or behavioral problems (severe: *higher use*), kinship care (*lower use*), and stranger care.

Most youth who have experienced maltreatment and removal from their homes are at extraordinarily high risk for mental health problems. It is generally accepted that the majority of them should receive mental health services regardless of current observable, or reported, behavior problems. If African American, Native American, and Latino youth are using services at lower rates, then they are being underserved relative to Caucasian youth.

What is...

Disproportionality: A particular group is represented in a system at a higher percentage than any other racial/ethnic group. For example, if five percent of the children in the foster care system are Caucasian, there would also be five percent of African American, five percent of Latino, five percent of Native American. A disproportionate rate is one where x percent of children in the foster care system are Caucasian; xx percent of children are African American, and xx percent are Latino, and xx percent are Native American.

Over-representation: particular racial/ethnic groups represented in a system at a higher percentage than they are represented in the child population. For example, 15 percent of children under 18 in the United States are African American, yet in 1999, 42 percent of children in foster care were African American.

Some studies conducted with the general population have shown no relationship between severity of mental health problems and likelihood of referral to mental health evaluation and services; others have addressed more specifically the extent of unmet need by race/ethnicity by examining the rates of service by severity of emotional or behavioral problems for race/ethnic groups. One of these studies, for example, showed that:

- Caucasians were much more likely to get services even when the total problem score was relatively low.
- African Americans demonstrated the strongest relationship between problem severity and use of services.
- Latino youth received relatively low service use across all problem severity categories.
- The rate of use for Caucasian in the lowest “need” group is about the same as the rate of service use for Latinos in the highest “need” group.

Several explanations have been offered to these disparities:

- Caucasian children are receiving services when clinical necessity is not apparent.
- The threshold for the perceived need (by parents or other sources) for mental health services is higher for ethnic minority youth compared to Caucasian youth.
- “Referability” of different types of behavior problems may be different in diverse cultures.

Barriers

Many different and potentially interacting factors, ranging from culturally driven differences in patterns to seek help, receptivity, and accessibility of providers to bias in referral and service delivery, create barriers to services including:

- Lack of minority mental health providers
- Cultural and language barriers
- Biased assessment techniques resulting in triage to alternative services

- Lack of knowledge about available services

In addition, biased referral patterns from “gateway” providers, such as teachers, health care professionals, juvenile probation workers, and caseworkers or judges in the child welfare system, may exist. These “gatekeepers” play an important role in getting children into mental health services.

But help-seeking patterns may influence the referral decision. While ethnic minority caregivers are as likely as Caucasian caregivers to identify children in need of treatment, they were not as likely to seek services. This may be due to cultural beliefs and preferences about formal mental health treatment or practical issues such as transportation or other children in the home needing care.

Differences in referral patterns may be based on perceptions of a family’s interest in mental health services. Caseworkers who are responsible for making recommen-

12 Steps to Lessen Disproportionality in Child Welfare

1. Establish a leadership group on cultural competency. Include executive leaders with visionary commitment to structural transformation.
2. Conduct an assessment: demographics of community, service population, governance, staff; current utilization patterns, client satisfaction rates, grievances; linguistic proficiency, interpretive and translation capacity; cultural knowledge of service population; organizational attitudes about culture, difference, and cross-cultural work.
3. Establish an organizational change plan tailored to the organization, with principles and values regarding cultural competency that might be unique to the organization.
4. Evaluate, refine, and create policies to promote principles that support the plan at the administrative and practice levels.
5. Institute human resource policies and practices that promote diversity among staff at all levels, establish cultural competency as an expectation of all staff and address the conflicts that arise among a diverse staff.
6. Establish strategies to accommodate the linguistic needs of the client population.
7. Establish ongoing training programs for all staff, including content on cultural knowledge of the service population; social and political issues of interest to the population; informal and formal resources in the community; personal attitudes, beliefs, biases and prejudices that promote or interfere with cross-cultural work; and cross-cultural skills.
8. Establish culture-specific intervention strategies to include traditional providers as indicated.
9. Create service strategies to promote easy access and a welcoming atmosphere.
10. Involve clients and community members in planning and evaluation.
11. Conduct ongoing evaluation and improvement.
12. Create a strategy for advocacy on behalf of and in conjunction with diverse communities to improve access, affordability, and appropriateness of service.

Vivian Jackson, "Cultural Competency," *Behavioral Health Management* March/April 2002, vol. 22, no. 2, pgs 24-26.

dations for referrals may be influenced by the family's or child's preferences or perceptions of the availability of culturally responsive (or linguistically appropriate) services. Caseworkers may also make assumptions about the benefits of psychotherapy for others of different cultural or racial/ethnic backgrounds.

Notes

Excerpted from papers and presentations at Research Roundtable on Children of Color in Child Welfare, September, 2002, sponsored by the Children's Bureau and Chapin Hall, Paper written by Ann F. Garland, Ph.D., John A. Landsverk, Ph.D., and Anna Lau, Ph.D. Presentation made by John Landsverk, Ph.D.

Sheryl H. Kataoka, Lily Zhang, and Kenneth B. Wells, "Unmet Need for Mental Health Care Among U.S. Children: Variation by Ethnicity and Insurance Status," *American Journal of Psychiatry*, September 2002, 159:1548-1555.

Elena P. Cohen, "Framework for Culturally Competent Decision-making in Child Welfare," *Child Welfare*, Vol. LXXXII, #2, March/April 2003.

Tough Questions and No Easy Answers

A mother talks about children's mental health

CINDY: My son, age 12, is now in a residential treatment center about 3 hours away from home. His current diagnosis is bi-polar disorder and obsessive-compulsive disorder. He has been in treatment in the mental health system since he was about 4 years old. He has been in residential treatment twice and hospitalized once in the past seven years. When we first entered into the system we were Medicaid eligible so it was a little easier to get services and get them paid. Since then we have been on private insurance, but private insurance has caps for their services. Families who need extensive mental health services, like us, usually reach their cap in the first three months of each year. This year was no exception. As we started school this fall we realized that his transition to middle school was going to be especially challenging for him because of his illness. His condition began deteriorating in school and at home. He had severe depression and suicidal ideation. We realized that long-term residential care was going to be the key, but I did not have the means to pay for it and my insurance would not cover it.

BP/NP: You said that he was Medicaid eligible and now he is not. What made him Medicaid eligible earlier?

CINDY: I was teaching school full-time. Then, because of his illness, I changed to substitute teaching to give me the flexibility I needed to help my son. But by not working every day, it put us in a lower income bracket so that we were eligible for Medicaid for two or three years. We have been on private insurance for six or seven years, now.

BP/NP: Has private insurance covered his mental health service needs?

CINDY: It covers a psychiatrist, therapy, in-home intensive therapeutic services, but there are limits. My insurance covers only 15 psychiatrist or therapist visits a year, so all our insurance benefits are used within three months. After that, families like us supplement it ourselves or your child doesn't get the services he needs and deteriorates.

BP/NP: What about public services?

CINDY: That's also available, but often on a sliding scale. Sometimes I could afford to continue and sometimes I cancelled his appointments because they were cost prohibitive. This really became a problem when we realized that he was going to need residential care. And we applied for special coverage insurance, but they won't cover it, and the pub-

lic area mental health system could not cover long-term residential care either.

BP/NP: What options were presented to you?

CINDY: In one of our child and family team meetings at mental health, the team suggested that the best way for us to get the services our son needed was to have child welfare take custody of him. They explained that child welfare could mandate the services he needed. This team is made up of a case manager from the mental health system, my son's teacher and principal, and his therapist. Often the school system suggests relinquishing custody when they know that more help is needed than can be offered at school.

BP/NP: What was your reaction to this suggestion?

CINDY: "Absolutely not!" was my first reaction. But, as his condition deteriorated, I thought "Maybe we need to think about this." It was a matter of his safety. We feared his possible suicide more than anything. He was aggressive, and he could have injured his siblings, but mostly his aggression was self-inflicted. As a parent you have to think, "What is going to save his life? To get him help, I may have to give up custody of my child. So I had to think 'maybe.'"

BP/NP: While you were considering this option, were you looking for others?

CINDY: I looked for other funding to pay for his residential treatment. We began the admissions process. I knew he needed this care even if it meant relin-

quishing custody. But I had not spoken to child welfare. The mental health center did talk to child welfare about my son, but I was holding out, refusing. But they were gathering information. They were making sure that I would be involved in any decisions being

made about his care, I would have visitation, that my son was not being removed from my care because of neglect or abuse, and they tried to explain that the situation was not as grim as I thought it was. If he became a ward of the state or child welfare, it was about funding, not about my parenting. I was still unsure about it, but I knew I had to consider this.

BP/NP: Was child welfare trying to present relinquishing custody as a positive option, that was not a judgment about you, but a service to you?

CINDY: Yes, but I found out that our state had some money for a comprehensive treatment program, that it was a system of care state program. Monies to help pay for treatment were set aside for children who were not eligible for Medicaid. But I had to find this out on my own, it was never offered to me as an alternative or to anyone I know. I talked with the mental health system myself. I have an advantage over other families, because I worked in a related mental health field, I am part of a statewide family advocacy group and have attended some of the statewide system of care collaboratives, so I just got wind of some of these possibilities.

BP/NP: Did the mental health staff on your team know about this program, or did they think that you were not eligible?

CINDY: The case manager may not have known it was available, and the others on our team



just didn't think about it. This program doesn't pay for all of his care; I will probably be paying off this debt for as long as I live, but I decided I was willing to go into that level of debt. I don't know what this is going to really cost me monthly, or what is the total cost for his care. I just try to pay off some of it. I have been asking for itemized bills, but have never received one.

BP/NP: Do you object to the idea of relinquishing custody?

CINDY: Absolutely! I don't understand why relinquishing custody has to be an option. There should be other ways to get the services you need for your child even if you have the inability to pay. Everyone should be able to find out what these options are.

BP/NP: Do you have any specific recommendations that might affect the public policy for changes?

CINDY: The state employees should be informed about what is available for assistance to families, and that relinquishing custody should only be offered as a funding opportunity only as a last resort, if at all. There should be public policy about educating families about available options. The average family would not have known where to look, as I did, to find funding to care

for a child like mine. Families and staff need more advocacy, more training, more educating.

BP/NP: What do you see in the future for your son?

CINDY: My future is really just one day at a time. Now, I am focusing on his transition when he comes home. We have been working hard to have a more successful transition to home and school.

BP/NP: What is his attitude about school?

CINDY: Middle school was hard for him. He went into shock around the culture of middle school. He likes the environment of residential care because it is more structured and disciplined. But the strategies he has learned there to deal with peers, bullying, and teasing will not work in his middle school and he knows it. So, we have not prepared these kids to reenter society. He has been a victim of coming home and working his way back into residential or hospitalization. He and others are caught in a cycle. Culturally, we have not fixed that part of the system. Being in a residential home where there are very few African American kids, it's easier for him to say to them, "Hey, you are hurting my feelings." But he comes back to a middle school that is predominately African

American and Hispanic. It is a very different world.

BP/NP: Did the team understand his concerns about this?

CINDY: Yes, but they realize that they do not have the training, the knowledge, to help him with that. And that it's going to be a difficult transition. He even asked, "How am I going to explain to my classmates where I have been for the last 6 months?" We have to get the script together.

BP/NP: Anything else we should convey to the child welfare community about this issue?

CINDY: Do they realize how humiliating relinquishing custody is to a family? It is not empowering to families. The message you give families is that you are not able to provide and care for your family. And we can. There should be a way to provide the funding without relinquishing custody. I don't know how that is done. It has to do with the stigma of what the child welfare system represents to most families. When you live in a community, in a neighborhood, when your child does not live with you, is not in your custody, people assume it is neglect and abuse. How do families retain their dignity in that process?



National Child Welfare Resource Center for Family-Centered Practice

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