This was a collaborative project between the National Abandoned Infants Assistance Resource Center (NAIARC) and Survey Center Focus L.L.C. (SCF). SCF is located in Chicago, IL (www.surveycenterllc.com).

Copies of the report are available at the NAIARC website (http://aia.berkeley.edu).

Please direct questions about the report to NAIARC at aiarc@berkeley.edu.
Parenting With HIV and Co-Occurring Disorders

FINDINGS FROM A FOCUS GROUP

Background & Purpose

A focus group was conducted in conjunction with a national summit on substance exposed newborns in Alexandria, Virginia. Participants included seven professionals representing the following organizations:

- Children’s Hospital of Philadelphia (Philadelphia)
- The Family Center (New York City)
- Health Federation of Philadelphia (Philadelphia)
- Family Options III: Families and Children’s Network (Chicago)

Specific titles included: project director, program coordinator, and manager. Participants had been in these roles ranging from 1 to 17 years.

The purpose of the discussion was to explore the parenting challenges that parents with HIV and co-occurring disorders experience, the subsequent challenges to social service organizations working with this clientele, and intervention strategies that help to strengthen parenting capacity among this population. This report summarizes the discussion elicited by key issues raised by the group facilitator.
What co-occurring disorders do parents living with HIV?

While the issues discussed in this report are intended to be relevant among HIV+ mothers and fathers, participants noted that it is almost always the mother who receives care.

Parents who are HIV+ often experience co-occurring mental illnesses or psychological disorders, as well as behavioral problems. Depression and/or post-partum depression is the most commonly identified disorder, which is often intensified by the many stresses of daily life. Participants estimate that between 80% and 95% of the mothers they treat are affected by depression. Other psychological conditions mentioned include anxiety, bipolar and psychotic disorders, as well as learning disabilities.

“We see a lot of depressive symptoms; a few of our clients experience bipolar disorder as well. I would say 95% of our cases have had some traumatic incident. Some are diagnosed with PTSD.”

“Mental retardation or maybe more accurately, borderline IQ and developmental or learning disabilities, go untreated and undiagnosed among some of these parents. Frankly, for adults it is almost impossible to address these issues without a diagnosis from childhood. I work with a parent who was infected at birth, she is nineteen now and is a parent, and I don’t know how she gets through the day.”

A variety of factors can exacerbate depression and anxiety among HIV+ mothers:

- Economic stresses add to the challenges of parenting, especially in an economic recession.
- Logistical complications, such as scheduling and getting to health-related appointments, contribute to the high occurrence of depression among this group.
- The shame of having the virus and a history of low self-esteem may lead to isolating behavior and contribute to feelings of depression. Due to the stigma associated with being HIV+, many of these mothers detach themselves from family and community for fear of being “found out.”
- Multiple pills must be taken, some with food, some without food, some in the morning, some in the evening—to many mothers, it can feel like life revolves around the timing of medication and meals. Moreover, the complexity of the medication regimen, in addition to the shame and embarrassment of having the virus, often deters mothers from taking their pills in the presence of others, making compliance a problem.
Anxiety driven by a lack of money, childcare and emotional support, as well as the frustrations of navigating complex insurance policies.

HIV+ moms who are taking their medications regularly oftentimes experience a lack of energy associated with depression and medications. This can make juggling the schedule of a newborn an exhausting and unmanageable task.

An HIV+ mother cannot breastfeed, and this can impact her sense of being a competent parent.

An important period of bonding between mother and newborn can pass, leaving both parties isolated or resulting in inconsistent attention and care for the baby from others in the household. This cycle is further complicated if the mother has other children who also need attention and has complex, absent, or inconsistent family support systems.

“Adding a baby who has been exposed and requires very strictly scheduled medication for the first six weeks to the adult’s adherence to medication regimen adds to the stress.”

“The lack of having those basic needs met contributes greatly to the stress levels of our families, and especially in this depressed economy where resources are even further limited, the stress levels are really just magnified.”

“There’s a challenge of getting adolescents to take medication because they don’t want to be any different than their peers, and if it makes you sleepy, groggy, or causes physical manifestations that you don’t want others to see or that you don’t want happening to your body—it’s very similar for the adults.”

Co-occurring Substance Abuse

Participants estimate that between 30% and 90% of HIV+ parents have a history of substance abuse, and that 10% to 35% are currently abusing substances. These estimates vary by program location, demographic characteristics of the population served, and which substances are included in the category. When alcohol is included, the figures are closer to the higher estimates of 90% and 35%, respectively. When co-habiting adults, consistent or otherwise, are considered, these estimates increase even more. It is not uncommon for a mother’s sexual partner, other children, or peripheral family members to be abusing substances in the presence of her and her baby.
“I think that in terms of past histories, either personal or with partners, I would say it’s quite high; probably around 60%. There’s a lot of substance use or abuse in people’s histories.”

“Something we’re also seeing with our families is that while Mom might not be actively using substances, if there are adolescents in the families, there is a very high percentage of adolescents who are actively using substances. Most of the time it’s marijuana; there is a lot of marijuana use going on in our families.”

“The mother might not be using, but the partner or the father of the children who are in and out of the house may be.”

For mothers who have stopped using substances, the psychological issues of depression and anxiety are triggers that may drive them back to their former pattern of substance abuse.

“What are the greatest challenges facing HIV+ parents with co-occurring disorders?

HIV+ mothers with co-occurring psychological disorders face myriad difficulties. One category is logistical—getting to clinics, keeping medical appointments for themselves and their children, making it to school functions (for older children), getting kids to school, and providing themselves and their children with basic needs. For mothers who receive income from government assistance programs, managing money over the course of a month is a challenge. Money is often spent in the first two weeks, leaving no resources to buy food or personal hygiene products for weeks on end.
In terms of keeping appointments, clinics are usually conveniently located, but are recognized in the community as HIV+ treatment centers. The stigma of associating with these clinics can make going there difficult as some mothers fear being observed and ostracized. Even in communities where more than adequate housing is available to those qualifying families, the mothers do not always take advantage of it because they do not want the community to know they are affected for fear of being shunned or, in some cases, verbally or physically attacked. On the other extreme, law offices and specialized mental health professionals are occasionally located in more affluent neighborhoods, which are not only hard for HIV+ mothers to get to but also intimidating.

“There’s stigma around HIV, there’s stigma around mental health. In D.C., everyone is connected. It’s a small population in a very small area, and a lot of our clients don’t want to go to clinics in their area because of the stigma surrounding HIV. They won’t go because people see them going into the building and they think they will say they have a mental health issue or are crazy.”

“The Catholic Church has built a lot of HIV housing, as groups of apartments, but when they were building there were big signs that identified it as HIV/AIDS housing. So the neighborhood knows about who lives there, the kids get rocks thrown at them, so of course they don’t want to live there. They continue to put some signs or some publicity around it, despite being approached by the parents, but they say they need to in order to keep their funding.”

“We have women who have acknowledged the fact that their mental health is impeding their parenting and they’re ready to go to a psychiatrist. We have some great psychiatrists, who accept Medicaid, but... they are located in a nicer neighborhood and it’s a pain to get from some of the poorer neighborhoods. If the buses are delayed, they’re worried about getting back before their kids are home from school. And if they have to wait because the psychiatrist is good, then even if they make it there, they might not know if they can stay because they have to be a parent. They have to get back in time.”

A challenge particular to those with existing substance abuse problems or a serious psychological disorder is the lack of multi-dimensional treatment support. HIV clinics are often not meant to be substance abuse or psychiatric service providers, yet parents with these problems need these additional services to be available locally and affordably.
“There is a lack of access to treatment support for substance use and mental illness. Most of these programs are not mental health service providers or subsidized service providers. I work at a medical clinic. There are social workers, people who meet with clients and provide counseling, but if someone has major depression or they have bipolar disease or if they are psychotic, they really need psychiatric help and they probably need medication. The access to that stuff is limited both concretely in that the access is not great, but people don’t want to go to those services. It’s hard to be invested in going to those types of things.”

In addition to the obstacles of location and stigmatization associated with going to HIV treatment centers, housing and services, the feelings of guilt and shame for exposing their children to the virus and for having it themselves are often triggered in these environments.

“And the guilt associated with a parent who is HIV+ and now they have a child who they are having to give this medication to. The baby doesn’t want to take it. They’re feeling guilty that they’ve potentially passed the virus to the child so now that further exacerbates all of the feelings they’re having about their depression and their self-worth and their self-esteem and it all gets muddied together.”

Another set of challenges include organic medical problems. Many mothers have co-morbidities, such as diabetes, that require complex treatments. For others, pre-existing conditions from previous lifestyle choices, including excessive drinking or drug abuse, can further weaken already compromised health conditions. Medications taken for co-occurring physical or mental illnesses often compound the lethargy of depression, sometimes to the extent that mothers cannot even get out of bed much less take care of themselves and their children. Additionally, when parents are in advanced stages of AIDS, dementia may set in.

“If I have a parent that is taking medication for HIV and she’s taking medication for depression and she’s taking medication for infection—trying to stay true to taking it when she’s supposed to and trying to fill the pill box up—it’s just a lot. A lot of it gets lost and she doesn’t want to do it anymore. They get real sleepy, too. They’re already really tired and can’t get out of bed from depression, for example. Then some psychiatrists will prescribe a sleeping medication and it will make them drowsy; then they really can’t get up.”
"We talk about people getting sicker on our case load, and I think they tend to be people who have extensive liver damage prior to the time they were positive. Or they've had other types of illnesses that are associated with substance abuse that have taken a toll even before they were positive. It could be a co-occurring illness, but there are other things going on with them health-wise that are aggravating their HIV status."

“We have a lot of older clients and we are starting to see this dementia that impacts their parenting skills. We see it with caregivers, too—older grandmothers, great aunts. Whether it’s from their former drug use, whether it’s the medication, whether it’s just them getting older, we seem to see it a lot. Anxiety is another reason, because a lot of our mothers have anxiety about the financial issues. Where is the next meal going to come from? Where are we going to live next month?”

“I’m also talking about dementia in the hospital, if they’re in hospice.”

The relationships in an HIV+ mother’s life are another source of challenges. In many instances, there is a multi-generational pattern of trauma in terms of abuse and violence. Such a history often gives these mothers a callused attitude toward life. When intimate partners who are abusing substances (especially alcohol or cocaine), are violent in the home, many women feel alone without support from family or community. Some types of abuse and trauma these mothers have experienced as children or young adults include sexual abuse, isolation, being locked in closets, deprived of food, denied use of a toilet, and witnessing siblings or other family members being abused or even killed before their eyes.

“That’s a big cycle. A lot of parents experienced trauma and bad parenting from an early age, just being in the city in an environment that is very unhealthy. A majority of my clients have been severely sexually abused, neglected to the point that they have been denied the use of a bathroom in their own home; they’ve been locked in closets, not given food, abandoned by their family, lived in neighborhoods with massive gun violence, had siblings murdered on the street and seen their bodies. A lot of them have turned to substance abuse, or they’ve built up a barrier and are hardened by what they’ve seen and have a hard time relating to their children. It’s a street mentality, like “look at what happened to me as a result of this.” It’s a very love/hate relationship with their children, and I really see that as a result of the experiences they have been through.”
With little firsthand experience with supportive relationships, these mothers often lack the knowledge of basic parenting skills that others learn by example. They were not parented well and oftentimes have only painful memories of childhood. Some mothers may resent their child, assuming that he or she will manipulate and abuse them just as everyone else has. Other mothers try to compensate for the guilt of transmitting the disease by spoiling their children. This usually means a lack of discipline, allowing their children to do, eat, and say whatever they please.

“\textit{The guilt is such a strong feeling for these parents. It can play both ways; a parent may want to spoil the child, for lack of a better word. This means let them do whatever, no structure, no boundaries, because they feel so guilty that they transmitted the illness. A lot of the families that we work with are low-income and may lack the parenting skills to begin with. The way they were parented was a little lacking and they pattern this same style.}”

**Exacerbating Conditions**

The relatively common challenges identified above often are exacerbated by personal circumstances of some parents with HIV.

Some HIV+ parents are first or second generation immigrants; their parents, grandparents or aunts/uncles may be available to provide care for the HIV+ parents’ child, but they often have significant language and cultural barriers. Social roles can clash between the generations, for example, a grandmother who has always been in charge, or an expectation that men do not wash dishes, etc. Such cultural clashes can undermine the HIV+ parents’ authority or the emotional support or structure for the family.

When HIV+ parents have learning disabilities, another layer of hardship is added, especially when they have gone undiagnosed in childhood. When literacy and/or basic math skills are lacking and money is limited, it is easy for a single incidence of overspending to lead to lack of food and, before long, the intervention of child protective services. The threat of losing custody of their child further denigrates already low self-esteem among this population.
They’re already very poor. Any [instance of] not going to your WIC appointment, any overspending puts you at a real risk for not being able to have food in the house at the end of the month. Your SSI check comes at the beginning of the month, and then at week three you’re done. You get redirected to a food bank, and that can be sustainable for years, but it’s a very fragile circumstance.

**Do co-occurring disorders impact an HIV+ parent’s ability, willingness, or readiness to make legal plans for his/her children?**

Without established routines or obvious reliable caregivers, it is a challenge to decide upon an appropriate and willing person to care for children after the primary parent is no longer able to perform the responsibilities of parenting. The task is often long and difficult.

Another challenge to making legal plans is the negative attitude that some of these families harbor toward the legal system, fostered by previous negative experiences. With little comprehension of how such a system might help them, it seems unapproachable and dealing with it is often put off or avoided.

**How else do parents’ co-occurring disorders impact their children?**

In addition to impacting the legal plans for their children’s future caregivers, HIV+ parents’ psychological disorders and potential for substance abuse have numerous ramifications in the daily lives of their children.

Participants strongly emphasized that a legacy of multi-generational trauma is often the root of these parents’ psychological disorders. Because of their own experiences, or lack thereof, they have little ability to bond with their children and to act as consistent and skillful caregivers. The absence of parent-child bonding is due to the lack of firsthand experience with supportive and healthy relationships, creating a love/hate dichotomy of emotion toward their children. Their own
hardships have contributed to their “street mentality.” Rather than reinforcing positive behaviors, they are more likely to warn their children of the world and the way it is, instilling fear with the threat that the child’s life might turn out as “upside-down” as their own life. Their mistrust of others leads some mothers to believe that their children will take advantage of them in the same manner. It is difficult for them to get past the damage of their own trauma despite the natural love they inherently feel for their babies. There is a general withdrawal from parenting that spans not only with emotional closeness, but physical proximity as well. Just “being together” is rare in a family like this. The mother may prefer to be alone upstairs while the children are downstairs. She might leave the stroller on the opposite side of the waiting room at the doctor’s office, too caught up in her own problems to see the needy child in her care.

“They’re so in their own thing, or their stigma, that they have a hard time making a connection. Mental illness and substance abuse really prevent people from making a consistent emotional connection with their child.”

On the same topic of trauma, these legacies almost always continue, to some extent, in the home lives of these parents. Children are, thus, likely to be exposed to the same types of violence and abuse that their mothers saw and felt as children, launching a repeat of the same cycle.

“We see a high prevalence of intimate partner violence in the home, so there are risks and safety issues. Safety issues and threats are usually addressed by child protective services, but when there are only risk issues, there is still potential for neglect of the children.”

When HIV+ parents have co-occurring depression, their parenting style is characteristically withdrawn, as described above. Parents with manic depression usually exhibit long periods of depression interrupted by short fits of mania. The depressive periods are typified by withdrawing from parenting responsibilities; and, while children may perceive the racing manic periods to be fun, frightening, or both, the unpredictability and inconsistency of a manic depressive parent’s behavior does not allow children to anticipate consistency in the care they receive or in the routine of life.

Psychotic illnesses are usually the most frightening for children to observe in their parents, as they are even more unpredictable. HIV+ parents suffering from various psychoses may hear voices and have hallucinations during the normal course of their day and can enact frightening and
confusing behaviors. Such behaviors can scar children emotionally who adopt their own coping mechanisms including “acting out” at school or withdrawing socially. The children’s behaviors can induce a parent or caregiver’s overreaction in the form of anger or even violence.

“*As kids get older, these kinds of effects can actually make the situation worse because they are responding to their experience. Whether it’s that they’re not doing well in school, or emotionally acting out, or withdrawing… however they’re trying to cope, it can produce more stress.*”

While older children of HIV+ parents affected by psychological disorders may voluntarily skip school as a coping mechanism, truancy in school is often a problem for younger children because of the parent’s inability to get the child to school.

Improper hygiene and nutrition is another serious ramification in the lives of these children. Food, healthy or not, may be inconsistently available and meals are unlikely to be regular or routine. With high truancy rates, little help with homework from parents, exposure to trauma, and lack of proper nutrition or supportive relationships, these children are at risk of following the path of their own parents.

“The basic needs are not met. When you’re talking about the safety and well-being of children, sometimes there’s no food, clothing, or housing. It has such an impact on day to day routines and the functioning of a family because the parents are not present.”

“In terms of the effects that depression has on the children and on the parent’s parenting style, I see a lot of the children taking on the role of parents—cooking, cleaning, washing dishes, helping the younger kids with homework, guiding the younger siblings, protecting the household. The oldest son will take on the role of the man. I see a lot of parents not being able to take their children not only to school, but to medical appointments, to school trips, to anything.”

Substance abuse during pregnancy may contribute to developmental disabilities in these children, but the parents do not have good parenting role models to draw on to know how to help their child. In the case of a disability like autism, it becomes even more difficult as the child may not be able to communicate his or her needs.
“Many of the parents have histories of substance use. Their substance use is a continuing issue. There’s a threshold beyond which a child would be removed from their home, so it is a very “in flux” and unstable situation. If they still have their kids and they’re using, there’s a back and forth about ’are the kids safe?’ That’s a challenge. That’s also true with mental illness. That’s true for many patients if they have those histories or diagnoses.”

“We have a few children who are HIV infected who also have severe developmental delays, and at the same time the parent does not know how to help the child or how to parent the child because of an autistic diagnosis when the child may not be able to communicate what he or she wants.”

Dementia is also seen among caregivers, other than the biological parent(s), who may be older family members. This can further complicate the family structure as they might not remember to get children to appointments or understand the importance of participating in programs themselves.

Separate from dementia, older caregivers such as grandparents or even foster parents who support the HIV+ parent may be out of date with current parenting practices and technology. Such gaps are further complicated if they are in denial or misinformed about HIV transmission and prevention.

“We have seventy year old women raising kids these days; our world is completely different from when they were parents the first time. The added technology and sexuality of our children are unknown to this population taking care of our children and we’re not educating them about prevention; we’re educating our youth. Their limited knowledge of what kids are doing and seeing, and what STDs are out there… what HIV means… a lot of our families are disclosed to, but they don’t know how to support the HIV+ people in their families.”

HIV+ parents are unlikely to disclose their condition, or that of their children, to others because of the stigma and resulting repercussions, both physical and emotional. For a child, this means that schools are likely not informed and, therefore, may not be as cognizant of the child’s needs and limitations.
What are the barriers to providing effective parenting interventions with this population?

The parenting skill curriculums utilized by these programs are valuable, yet may be seen as irrelevant because of cultural (differences). Families with different cultural norms may dismiss some suggestions as inapplicable, but would be receptive to more individualized, tailored suggestions. On the same topic, parenting is more than a set of behaviors or “skills” that can be described in a pamphlet. It is difficult to convey bonding without present and ongoing human interaction and guidance.

In general, paying for programs is a problem for all families, but even more so for working families versus those on Medicaid. Healthcare policy changes can create additional financial barriers for these families, leading to additional stress and anxiety. In New York City, HIV+ individuals were exempt from Managed Care; yet beginning in August 2010 they will be required to use physicians from specific providers unless they qualify for another exemption such as homelessness.

“Now with this switch that’s going to be starting in August and phased in over a six-month period, a lot of our families are concerned about whether or not their physicians are in those plans and what that will mean for their care. This is a whole other level of complication that these families are going to have to deal with. I think the next few months are going to be additionally stressful for our families.”

Reluctance of disclosing their situation is another barrier to providing services for these families. Anxieties about reactions from employers, community, and family members keep many HIV+ parents silent and make support even more elusive.

“On the issue of disclosure, it has an impact on everything. It’s not only disclosure of HIV, but also of medication for a child. If they have not disclosed to anyone, there will be limited support systems.”

“Everything is on the Internet now. Many individuals have said they didn’t disclose, but they didn’t hide their medications well enough, and so someone found the medication and it goes in the computer—and boom—now their HIV status has been revealed. So, if I am going to take these medications, they have to all be in different kinds of bottles so [no one will know what I’m taking and then] everything gets all mixed up together and you get confused.”
What intervention models have effectively improved parenting skills and practices among this population, or have effectively supported these parents through the permanency planning process?

- **PCIT-based (Parent Child Interaction Therapy, see: [http://pcit.phhp.ufl.edu/RecentLiterature.htm](http://pcit.phhp.ufl.edu/RecentLiterature.htm) model)**
  - Especially for busy parents
  - Involves devoting a specific amount of time each day to each child
  - Lets the child lead by doing whatever he or she wants
  - Parents participate by simply being present physically and mentally
  - Parents should avoid being directive and instead take a passive role of guiding their children if needed but, most importantly, signaling their interest by being occupied by their child

- **TREM model: Treatment, Recovery, Empower, and Model**
  - Substance-abuse focused
  - Tools to improve ability to deal with trauma

- **In-home visits (or other location chosen by family)**
  - Removes barriers such as childcare, transportation and stigma
  - Provides services in a safe and comfortable environment
  - Builds trust and support between the family and the agency

- **Partners in Parenting Education (PIPE)**
  - Addresses social and emotional development in children
  - Builds the parent/child relationship through in-home bonding

- **Multi-disciplinary teams to work with family**
  - Social worker, medical case manager, lawyer

- **Integrating support groups SELF curriculum**
  - Safety
  - Emotional management
  - Loss and future
  - Using non-linear models that can be integrated across topics
Groups: Isolation to socialization
- Helps isolated families come out and socialize
- Aids parent/child development
- Provides exposure to the community, such as a zoo visit
- Normalizes the challenges of infected families

Group Retreats
- Support group
- Individual on-site psychologist for independent consultations
- Breaks down the isolation: “This problem isn’t yours alone.”
- Allows parents to share observations with each other

Parents Matter!
- CDC parenting skill-based training

What additional resources might help programs better support the parenting needs of this population?

Appropriate funding is the paramount recommendation among professionals regarding resources that would help programs to better serve the population. While more funding is certainly desired, collaboration between funding sources could improve the disjointed nature of the current system. With more dollars and more collaborative funding sources, participants feel that they could not only improve the services they provide to their clients, but also serve more of the many families who would benefit from involvement. The idea of better collaboration extends to child service agencies as well. While participants recognized these agencies are overwhelmed, they still say it would be helpful if they could do more.

Finding experienced professionals to work with families is another manifold challenge. For one thing, the families being served may be culturally different than a novice social worker—those who are most likely to be working in these environments. A recent college graduate is unlikely to have the experiential knowledge of how to effectively interact with parents and children in these challenging situations despite their factual knowledge and good intent. More experienced professionals are usually less willing to provide the type of services required by this population, such as traveling to in-home sessions. Even if these families could afford to see a seasoned specialist with a private practice, the logistical challenges of transportation and the intimidation factor of
affluent neighborhoods would make it unlikely that they would go. Better access to appropriate mental health treatment would also benefit older children affected by their own psychological disorders along and the emotional turmoil of anticipating a change in living situation. Children old enough to realize they may one day acquire a new caregiver and home will likely feel scared and uncertain of their future, and may react in dangerous ways such as running away. An experienced and appropriate mental health professional would be of great value to families in these situations.

A greater ability to offer the service of in-home visits with appropriately skilled professionals would also ease the logistical challenge of getting families to commit to a program for any length of time. The unpredictability of life events can make getting to scheduled appointments difficult, especially for these parents. A parent’s genuine desire to help his or her family is not a guarantee of appropriate care; plans can be easily disrupted by the challenges of expense, childcare, concurrent trauma, and illness.

Finally, participants note that the ability to develop and offer some type of program to assist HIV+ parents to inform family, friends, and schools about their situation would be useful. It is very difficult for these parents to tell people they are HIV+, and while a disclosure program would not require parents to tell others, it would certainly offer support and ease the process.

## Conclusion

Co-occurring disorders among parents with HIV are pervasive and must be adequately treated to avoid serious mental, physical, and social ramifications for themselves and their children. Interventions must not only address the primary disorders, but also the commonly concurrent medical, social, and environmental challenges that can further exacerbate a parent’s mental illness and substance abuse. Untreated, co-occurring disorders can lead to a variety of problems in parents’ relationships and create barriers to proper utilization of HIV treatment. Moreover, children often are adversely impacted by their parents’ disorders and may require special services themselves to address attachment, mental health, academic, and health related problems. Given the various challenges parents with HIV face, successful treatment approaches must be comprehensive, individualized, and accessible to all family members.