Findings Brief 4

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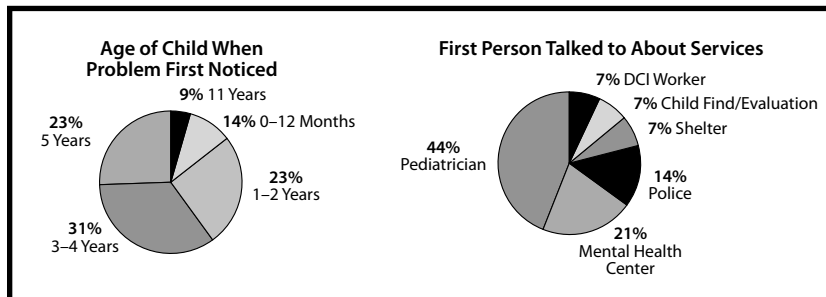
Family Experience of the **Mental Health System**

Pathways to Care

"You call here. You call there. And, then you got to call somewhere else."

There was no clear pathway to services for most of the thirty families who participated in the **Family Experience of the Mental Health System Study** (**FEMHS**) over the two-year period. Families reported multiple pathways to mental health services, with schools, specialty mental health providers, and physicians representing the key initial points of contact.

Although over 50% of the caregivers indicated that they noticed a problem with their children before age four, all families in the study were still seeking services even though the average age of the children when the study began was 9 years old. Sixty-two percent of families first sought services because of their children's behavior problems, with almost half of caregivers (44%) first talking to their pediatricians about their concerns.

Age of Child When Problem First Noticed
- 9% 11 Years
- 14% 0–12 Months
- 23% 1–2 Years
- 31% 3–4 Years
- 23% 5 Years

First Person Talked to About Services
- 7% DCI Worker
- 7% Child Find/Evaluation
- 7% Shelter
- 14% Police
- 21% Mental Health Center
- 44% Pediatrician

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While most caregivers were able to make some initial contact with special mental health providers (e.g., a community mental health center, individualized education planning process (IEP) or school based mental health team), families reported that they lacked information about the services these agencies or programs provided. As a result, they often called or visited multiple agencies before finding the help they needed. Where a family went after this initial point of contact and where they went to find information and sources of referral was often much more complex, with caregivers frequently hearing about these sources through word of mouth or happenstance.

"And the referrals and numbers; they keep connecting you to other places and send you other places. You call here, you got to call there, and then you got to call somewhere else."

Service referrals generally proved difficult to pursue, and families reported very limited choices, further complicating the pathway to services. Physicians would provide referrals for specific services, without offering the names of individuals or agencies that provide those services. Caregivers were often left to search for service providers on their own in order to follow through on the referral. Even when a specific referral was offered, caregivers would make contact only to learn that they did not provide the service, there was a long waiting list, or their children were not eligible.

"I'll be taking him however many times a week to a psychologist. I have a referral from the pediatrician, but no place to take him yet."

Among the study sample of thirty families, the study included seven African American families and eight Hispanic families. For the Hispanic families, their experiences with the pathways to care varied depending a large part on their language proficiency and immigration status and permanency.

The African American families said they did not experience any problems due to their race. However, they, and a number of other families in the study shared their feelings about being discriminated against by some providers or agency receptionists based on their low income or perceived lack of education. It should also be noted that the interviewers were not of African American descent. In one study, results suggested African Americans may feel uncomfortable talking about race related issues with non African Americans, therefore the response from these interviews may have been different if the interviewer was of the same racial/ethnic background. (Reese, 2003)

"Are you trying to say that the White people get help quicker than the Black? I think its so much red tape in trying to get help for anybody because they've always got the dollar sign on it or you ain't got enough money."

For Spanish-speaking families, this process was much more difficult, due to the language barrier and the lack of consistent translation services. Those families who spoke Spanish only talked about the difficulties in obtaining services from mental health providers in their own language. They talked about how they had to wait longer periods of time in the waiting room while an office manager or another staff member at the location was able to translate for them. They also mentioned that they sometimes preferred not to call and leave messages for providers since nobody ever returned their calls, and if they did, they answered after several weeks. Other families mentioned that they had to schedule interviews at the school

when a bilingual friend was able to go with them. One mother quit services due to lack of a bilingual staff person at the agency. She explained that she understood the difficulties of using her child to do translations and tried not to use her, since she knew sometimes the child did not tell her the truth about what the provider said regarding the child's condition or behavior.

Hispanic families also mentioned they felt they are sometimes discriminated against because of their accents. And, for those who were bilingual, most were depended on for translating and acting as liaisons for other Hispanics. One mother said she likes to help people, but sometimes organizations ask her to volunteer because she is bilingual. She shared with her interviewer that she was helping a lot of families and providers and not getting paid for it. This mother quit volunteering or accepting services from the organization after two years of involvement.

The pathway to services is often complicated by life's co-occurring events. For example, many families moved more than once during the two years of the study within the same city, requiring children to move to other schools and obtain different service providers.

"The social worker's supervisor came home with the therapist. I asked for a bilingual social worker and the supervisor said they didn't have one in my area. She said it was my choice to leave the program since they couldn't give me one."

"I don't have an accent so I have no problem, especially on the phone. There is a problem with that though, because my mother faces it when she goes to certain places. It has to do with the language, especially if a person carries a strong accent. They get discriminated against. It's something that you witness wherever you go."
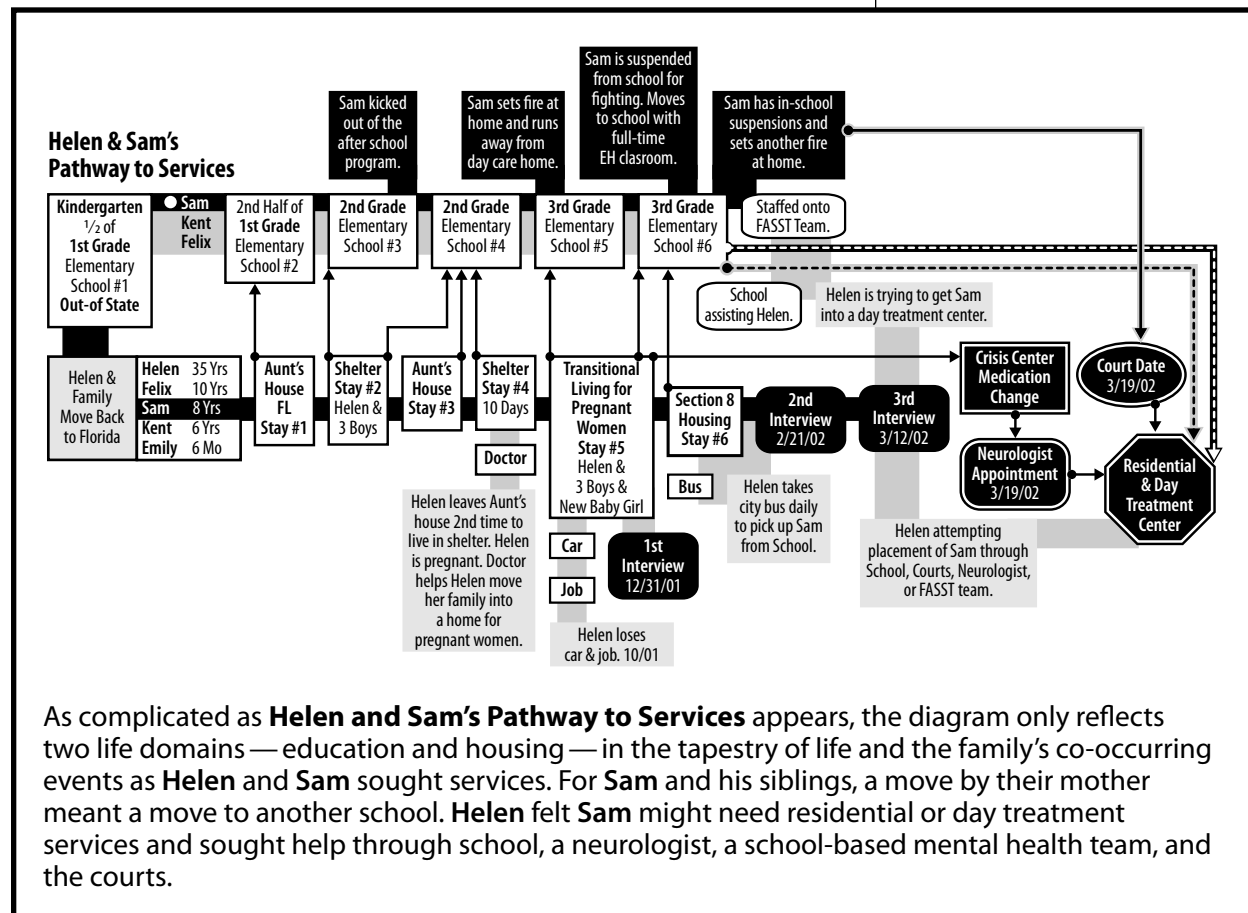
As complicated as **Helen and Sam's Pathway to Services** appears, the diagram only reflects two life domains — education and housing — in the tapestry of life and the family's co-occurring events as **Helen** and **Sam** sought services. For **Sam** and his siblings, a move by their mother meant a move to another school. **Helen** felt **Sam** might need residential or day treatment services and sought help through school, a neurologist, a school-based mental health team, and the courts.

Families moved for several reasons. Some moved within the same area looking for safer neighborhoods or to be closer to other family members. In any case, a move often included a change in service provision. The family who quit services after being unable to be assigned to a bilingual worker did so after moving to a new location within the same city where bilingual staff was unavailable. Another mother opted to send her children back to her native country since she felt it was easier, faster and less expensive to get services there than waiting for the assessments to be done here in the US.

There appears to be no clearly defined mental health system through which families can access services. Mental health needs to do a better job of establishing itself as a mainline system of care, reinforcing the importance of incorporating education about mental health services to address stigma, and about the relationship of cognitive, physical and emotional development.

What the Research Says

A goal for the behavioral health community has been to provide a more organized pathway to services and supports rather than the often fragmented delivery systems families too frequently navigate. An organized pathway does not necessarily mean a single point of entry or multiple points of entry into a service or system of care, but rather an approach whereby families do not have to navigate multiple systems to obtain care and re-navigate systems every time services and supports require change (Pires, 2002). The delivery of behavioral health services to children and youth and the pathway to care are subjects that have received closer scrutiny in recent years (Sayal et al., 2002; Pescosolido, 1997). Goldberg & Huxley's (1980) **pathways to care model** for psychiatric services, Rosenstock's (1966) **health belief model**, and Andersen's (1968 & 1994) **socio-behavioral model** have helped to conceptualize the processes and activities of seeking services. However, studies continue to show that most children who are in need of behavioral health services do not receive them (Burns et al., 1995; Leaf et al., 1996).

Findings from the FEMHS study suggest that professionals who serve children in everyday settings, such as in schools and health centers, as well as lay people involved in neighborhood activities (e.g., police officers, coaches, recreation counselors) are increasingly being called upon to identify youth with possible mental health problems and to play a role in seeking help for these youth. Stiffman and associates (2000) found that professionals who come into contact with youth are most likely to refer youth for mental health services when they feel capable of making a mental health assessment of the child, and when they are familiar with the mental health services available in the community for that child. In assessing the public's recognition of mental disorders and their beliefs about various treatments, Jorm and associates (1997)

concluded that in order for mental disorders to be recognized early in the community and appropriate intervention sought, the level of mental health literacy needs to be raised, including the understanding of psychiatric treatments.

Over half of the families in the FEMHS study sought help from their pediatricians. This finding reflects current research that most children with psychosocial problems are diagnosed and treated by primary care physicians rather than mental health specialists (Gardner et al., 2000). These studies note that rates of primary care physicians identifying mental health problems in children are low, and, more than half of the children who are referred to specialty mental health by their primary care physician never make it to the specialist (Kelleher, 2000). For this reason, The **President's New Freedom Commission on Mental Health** (**2003**) emphasized the need for better coordination between mental health care and primary health care, and the U.S. Surgeon General has specifically called on pediatricians to improve screening and referral for child mental illness.

It also should be noted that other studies, including the FEMHS, found that medical personnel do not constitute the major source of referral to mental health services for children and adolescents (Jaffa & Dezsery, 1989; Gullotta & Noyes, 1995). Children are referred to mental health services through a much broader referral base, for example, through social workers and schools. This is different from referral pathways for adults, where the likely referral to a mental health service comes from a general medical practitioner. Studies also find that schools are the primary providers of mental services for children (Hoagwood & Erwin, 1997)

The pathways to care for mental health services for children are diverse and are dependent on sociocultural and economic factors. Mental health utilization varies across racial/ethnic groups, and the reasons for these disparities are being more closely examined than ever before. For example, according to **A Supplement to Mental Health: A Report of the Surgeon General** (**2001**), racial and ethnic minorities have less access to mental health services than do whites and are less likely to receive needed care. This report identified a number of barriers to care for racial and ethnic minorities including: cost of care; societal stigma; fragmented organization of services; clinicians' lack of awareness of cultural issues, bias, or inability to speak the client's language; clients' fear and mistrust of treatment; and, minorities historical and present day struggles with racism and discrimination, which affect their mental health and contribute to their lower socioeconomic, social, and political status.

Research is increasingly focusing on specific racial and ethnic populations, as well as service use differences between families living in urban and rural areas (Angold, et. al, 2002). For example, Ringel and Sturm (2001) found that Latinos are the least likely of all groups to access specialty care, even though they and Black

children have the highest rates of need. They found reasons for the disparity include mistrust of the health system, language barriers and lack of insurance, with 30% of Hispanics likely to be uninsured. Research finds that people with health care coverage have greater access to services than those who do not (Newhouse, 1993). In a study of African American and Caucasian children, Bussing and associates (2003) found that potential barriers to services included no perceived service needs, system barriers, negative expectations, stigma-related, and financial barriers.

The **President's New Freedom Commission on Mental Health** (**2003**) specifically addresses the need to improve access to quality care and services by transforming the mental health service delivery system by "providing service and treatment that is consumer friendly and family centered, and by focusing on increasing consumers' ability to successfully cope with life's challenges, on facilitating recovery and on building resilience, not just managing symptoms" (pg. 5). Mental health reaches into every avenue of a child's life, and it will take every avenue — education, community, spirituality, work, recreation — to help create pathways to mental health care that are effective and efficient. Research needs to continue to examine factors that influence access to care, increase our understanding of help-seeking behaviors, and provide guidance as community systems of care are built to address the mental health needs of children and their families.

System of Care Checklist: Pathways to Care

- ☐ Families know who and how to call to access service for their child with mental health needs.
- ☐ All aspects to accessing services are culturally and linguistically competent.
- ☐ Families are treated with respect and regarded as experts in knowing their children.
- ☐ Pediatricians and other initial points of contact and referral are aware of services and can make an accurate referral recommendation to the family for further mental health assessments.
- ☐ Eligibility requirements for specific programs are very clearly communicated to families and referral sources.
- ☐ Policies are in place that help systems of care, with multiple service providers, create clear service pathways.
- ☐ Policies are in place to ensure that every child in need of mental health service is able to access them.
- ☐ Policies are in place that can help families, agencies and providers address the racial and ethnic disparities in mental health service utilization.
- ☐ Current or proposed changes to mechanisms, such as managed care, designed to organize, deliver, and pay for health services need to increase access to care and promote evidence-based quality care, emphasizing prevention.
- ☐ All families have access to mental health services without having to navigate multiple systems.
- ☐ All families are able to make changes to service or treatment plans without having to re-navigate the system.
- ☐ Policies are in place to support establishing mental health as a mainline system of care, reinforcing the importance of incorporating education about mental health services, services to address stigma, and about the relationship of cognitive, physical and emotional development.
- ☐ Professionals who serve children in everyday settings have access to current information about mental health and mental health services and treatment.
- ☐ The pathway to care for mental health services recognizes and responds to socio-cultural and economic factors.
- ☐ Barriers to care are identified and appropriately responded to.
- ☐ Creating effective and efficient pathways to services is seen as a community responsibility, including the schools, courts, child welfare, and physical and behavioral health.

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