



Overcoming Barriers in our Community

How are we doing?

Parent/Professional
Advocacy League
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PAL

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Parent/Professional Advocacy League (PAL) is the leading public voice for families whose children have emotional, behavioral and mental health needs in Massachusetts. PAL is the state organization of the National Federation of Families and is dedicated to promoting change that will improve the children's mental health system statewide.

Overcoming Barriers in the Community

How Are We Doing?

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The logo for the Parent/Professional Advocacy League (PAL) is rendered in a bold, black, hand-drawn style. The letters 'P', 'A', and 'L' are thick and slightly irregular, with the 'A' having a small loop at the top. The letters are positioned centrally on the page.

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Executive Summary

In November 2008, Parent/Professional Advocacy League (PAL) invited parents whose children had emotional, behavioral and mental health needs to participate in a survey. The primary goal was to listen to families in Massachusetts and better understand the barriers they identified when accessing needed treatment for their child. The short, 16-question survey queried families on a wide range of topics, such as the overall and economic barriers to accessing treatments, ability to coordinate care for their child, respite care, access to school services, effects of stigma and resources and treatments that were most effective.

The survey was completed by 471 parents (and a few professionals) over a 6 week period. 49% of respondents also wrote short and long comments, often detailing their concerns, struggles and successes. Survey respondents were either parents connected to PAL's network or who participated in a listserv or email discussion group. 65% stated that their child had private insurance while 55% had MassHealth (more than one answer was possible).

Summary of Findings

Out of pocket expenses. One of the most striking findings was the impact of out of pocket expenses on families as a result of their child's mental health care. Parent comments echoed a 2008 study by The Center for Studying Health System Change, which reported that there is very little cushion in most family budgets for health care costs.

- 32% of respondents said their child needed a treatment their insurance didn't cover which was a significant expense
- 30% responded that the copayment for therapy was difficult to afford and almost 25% found it was difficult to pay for their child's medications
- 25% reported that they couldn't find a local provider who accepted their insurance leading to associated costs for gas or time off from work

Respite care. Respite care has been shown to be a key component in the overall treatment of children with mental health needs. It is often highly valued by families. However, many parents responded that they had never heard of respite care.

- 19% of parents had never heard of respite care
- 75% of respondents found it to be at least moderately important
- 60% of those surveyed found respite to be very difficult to access

Other barriers. Many families identified multiple barriers (aside from out of pocket expenses) to accessing treatment and services for their child. These obstacles ranged from getting a clear diagnosis to delays in services.

- 61% reported that they had experienced long waits to get an appointment for their child
- More than two-thirds reported difficulty getting a clear diagnosis for their child and one-third found it very difficult
- 40% found it difficult to obtain useful information about the options available to them

Helpful resources. Parents value resources and information that can assist them with accessing services, reducing their isolation and helping them make the best decisions they can for their child and family.

- Parents overwhelmingly reported (71%) that the most helpful resource was other parents
- The internet (58%) and magazines, books and other print media (55%) were rated highly

Effective Services. While many parents struggle to access services and treatments for their children, many families also reported that the services they finally received were effective.

- 41% described how the services made a difference
- 70% rated medication as the most effective treatment, followed closely by therapy (58%)
- 28% reported that wraparound had made a difference and 24% said that parent-to-parent support was an effective service
- 36% reported that they were still looking for effective treatments and services

Schools. Children spend a significant part of their day in school and their success is dependent on both adequate supports and staff who understand their mental health needs. Many parents reported that schools fell short of the mark.

- More than 30% responded that it was very difficult to obtain access to necessary school services for their child
- Although 37% of parents believed that school staff recognized and understood their child's mental health issues, another third rated the school staff as poor to very poor in their understanding

Stigma and impact on the family. The responses describing how stigma had caused negative outcomes were the most poignant.

- Almost 70% of respondents reported that their child's behavior was seen as poor parenting
- 40% felt that their extended family made them and their child feel unwelcome
- 24% reported that the impact on their family was significant

Conclusion

Families raising children and youth with mental health needs face daunting challenges. They struggle to get a clear diagnosis, comb resources online and in a variety of materials and wait for extended periods of time, sometimes even years, to access the treatment and services their child requires. Many families also report that their out of pocket expenses are also challenging. They can be forced to choose between paying other bills, cutting down expenses or delaying other medical care in order to pay for their child's therapy, medications or other necessary treatment. National data shows that they often pay more costs than parents whose children have significant medical disabilities.

Furthermore, they encounter a lack of understanding of their child's mental health challenges at every juncture. School staff and extended family alike often blame them for their child's behaviors. As one parent pointed out, "On the one hand, parents are encouraged and even called neglectful if they don't seek treatment for their children, but then they are accused when the system fails to help and causes even greater harm."

Despite all this, parents wrote again and again how much they appreciated support, excellent resources and effective services. It was striking to note that the most valued resource was another parent, especially one who had already been down the same road. Treatment that positively impacted their child was highly valued. While a hard won success is often sweet, families of children with mental health needs simply want someone to help them identify services that work, ensure that it's affordable and streamline access. That's all any parent wants.

Introduction

“The children’s mental health system is broken.” We’ve all heard this comment before or said it ourselves. However, is it really true?

What is true is that families struggle, often heroically, to get the treatments and services their child needs. They make multiple phone calls, surf the web or browse through pamphlets and books to find useful information. They put their name on wait lists and try to gauge whether a service will really be effective. It’s often an arduous task just to get in the door.

What is also true is that families report that many services are working. They find a treatment or school setting that truly helps their child make progress. They find support for themselves that ends up being more than support; it builds skills, identifies resources and creates a safety net.

What is true is that it is financially overwhelming to raise a child with mental health needs. Results from a national survey of children with special health care needs indicate that families of children with emotional, behavioral and developmental conditions seem to pay more out of pocket than families of kids even with substantial physical diagnoses. Families in our survey echoed this finding over and over again.

What is true is that parents continue to deal with the misperception of others, often in their own families, who think their child’s behavior is the result of something they did or didn’t do. They face a lack of compassion, a feeling of being blamed and hurtful stereotypes.

What is also true is that with the advent of the internet, families are finding more resources that help. Not only are they able to get information and support from traditional sources such as therapists, but they are able to tap into reliable information and support online. Good information helps arm parents who are working for good outcomes for their own children and systems change for all children.

The children’s mental health system in Massachusetts is undergoing significant change. New services have been put into place through the Children’s Behavioral Health Initiative. Mental health treatment for children emphasizes more effective treatments in the home and community. Families know what is working for them and where they encounter barriers. As we redesign and reform a system some call “broken,” it’s time to incorporate the knowledge and experience of families in that design.

Methodology/Demographics

Methods

In November 2008, PAL invited parents whose children had emotional, behavioral and mental health needs to participate in a survey. The primary goal was to listen to families in Massachusetts raising children with mental health needs and better understand the barriers they identified when accessing needed treatment for their child. A pilot survey was first developed and distributed to a small group. Using their feedback, a final survey was posted through an online survey instrument (SurveyMonkey). The link to the survey was distributed through the PAL Network and through various liststervs and email lists (Mass Family Voices, Adoptive Families Together and MassPAC). Paper copies of the survey were distributed through PAL support groups and upon request. Professionals passed surveys along to parents in their own localized networks, representing a diverse cross-section of geography, socioeconomic status, and ethnicity.

The 16-question survey asked parents structured questions about a wide range of topics, such as the overall and economic barriers to accessing treatments, ability to coordinate care for their child, respite care, access to school services, effects of stigma, and resources and treatments that were most effective. Answers were selected using a Likert scale. Qualifying questions were asked to establish the relationship of the respondent to a child with mental health needs, zip code (to confirm they lived in Massachusetts) and type of insurance coverage the child currently had. At the end, there was an optional open ended question. One survey was filled out per respondent.

The survey was completed by 471 parents over a 6-week period in November and December of 2008. Survey respondents were limited to families involved in PAL's network or active in online discussion groups. Because the survey was only administered in English, the sample size was limited to English speakers.

Demographics

Of the 471 surveys completed, 90% of respondents identified themselves as parents of children with mental health needs. More than one answer could be checked off. Other responses included provider of services (13%), family member of a child with a mental health need (10%), and 7% identified as a medical professional.

When asked to identify their child's insurance, 65% responded that they had private insurance such as Blue Cross Blue Shield, Harvard Pilgrim, etc. Approximately 55% of respondents had MassHealth. Again, more than one answer could be selected.

Out of Pocket Expenses

It has been almost two years since the country entered the most severe economic downturn since the Great Depression. The stock market has been volatile, financial institutions have lost the trust of the general public, and unemployment has hovered around 10% nationwide¹. The cumulative effects have been felt by rich and poor alike. The Massachusetts unemployment rate, although not quite as high as the national rate, is still much worse than it was two years ago, topping off at 9.5% in January of 2010, as compared to 7.4% in December 2008, and 5.8% in July 2008. The figure currently stands at 9.2% as of April 2010².

For families whose children have mental health needs, out of pocket costs associated with obtaining services and treatments for their child is unusually high. In this tough economic climate, the costs are magnified. A 2008 study by The Center for Studying Health System Change, reports that there is very little cushion in most family budgets for health care costs; financial strain increases substantially when out of pocket expenses total as little as 2.5% of family income. When interviewed, many families reported being forced to make difficult trade-offs with other family necessities, put off paying other bills, cut down on other expenses and delayed getting needed medical care.³

This data is consistent with feedback that PAL has received from family support specialists (FSS) throughout Massachusetts, who report similar decisions being made by low-income families in their network⁴. Families across

“We spend our savings on providers that insurance doesn’t cover.”

Massachusetts are requesting assistance with food, fuel and utilities more often. Many families who have been able to access scholarships for camps and other programs are finding that there are more families competing for fewer slots. One FSS reported, “Many of the families I work with are on some sort of public assistance, so I didn’t expect them to be affected by the economy since they are not the ones losing their jobs. What they have lost is the amount of assistance they get from food pantries, churches and other community help groups.”

One question asked parents to identify expenses that presented a barrier to accessing services needed by their child. Respondents were allowed to choose more than one answer if they experienced multiple barriers. The most often cited barrier (32%) were

¹Bureau of Labor Statistics. Retrieved on June 7, 2010.

http://data.bls.gov/PDQ/servlet/SurveyOutputServlet?data_tool=latest_numbers&series_id=LNS14000000

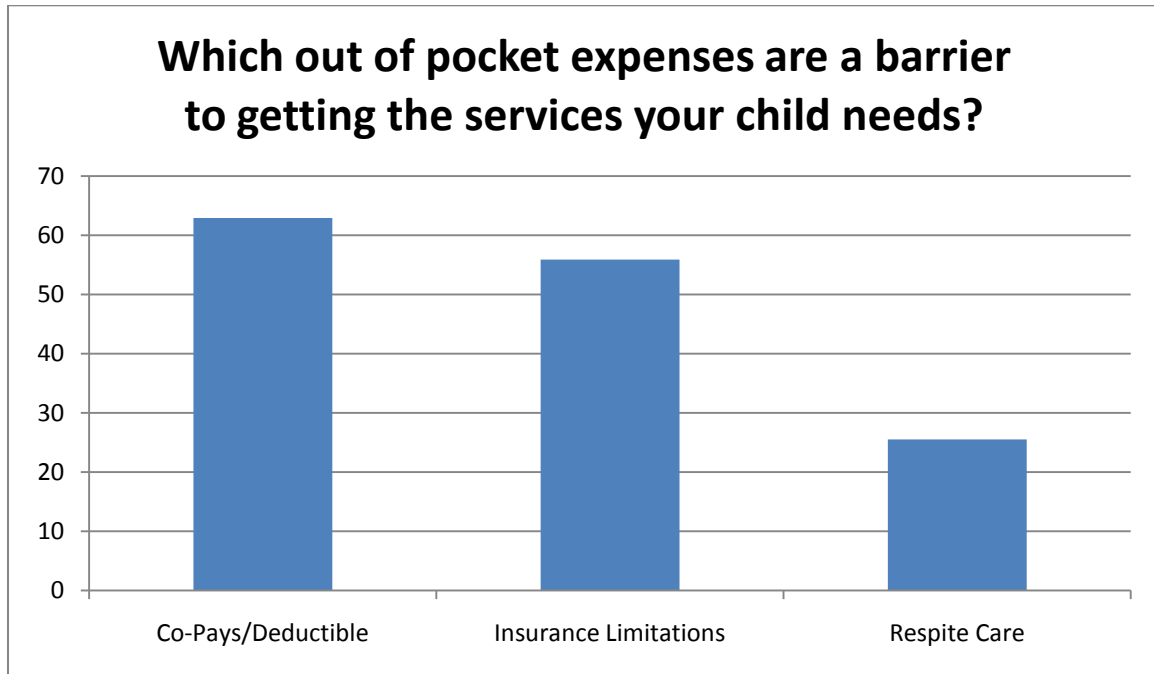
²Bureau of Labor Statistics. Retrieved on June 7, 2010.

http://data.bls.gov/PDQ/servlet/SurveyOutputServlet?data_tool=latest_numbers&series_id=LASST25000003

³The Center for Studying Health System Change Report

⁴PAL factsheet

the costs incurred by families when their insurance doesn't cover the services their child needs. These costs ranged from payments for therapy and medication visits to alternative therapies such as vitamins, supplements, acupuncture, etc.



Another common cost barrier was co-payments. 30% of parents responded that the co-pay for therapy or treatment was difficult to afford, and almost a quarter found it was difficult to pay for their child's medications. Parents cited different out of pocket costs, which skyrocketed when their child needed weekly therapy, multiple specialists and medications with high copayments. One parent wrote, "The costs of treatment, medications and clinical appointments are excessive."

Additionally, 25% of respondents reported that another factor was that the child's provider does not accept their insurance. This led to driving greater distances to find a provider who does (associated costs were extra gas, and time off from work), paying for the services out of pocket, or not receiving care at all. An additional 11% found that the cost of the initial deductible was very high.

For families that are aware of and able to access respite care (which are often barriers in and of themselves), more than 25% of parents reported it to be a significant expense, so that a break from the stresses of raising a child with mental health needs was unaffordable.

Unfortunately for numerous families, many of these cost barriers affect them with serious consequences. As one parent commented, "All are barriers. I've spent money I saved for college education for my child on mental health services."

Bad News, Good News

Although the cost of raising a child with mental health needs can be a major obstacle, other barriers exist that hinder the ability of parents and caregivers to offer adequate support for their child. From access to services, to lack of helpful information and resources and to the inability to get an accurate diagnosis for their child, all parents are impacted to varying degrees.

Easy access to both relevant information and a clear diagnosis are vital for parents to get necessary, successful treatments for their child. According to recent research in this area, the earlier a child's mental health needs are identified and intervention begins, the greater the long-term benefits⁵. When parents are unable to obtain an accurate diagnosis of their child, it often presents a formidable barrier, preventing them from accessing the appropriate treatments until they can know what exactly is wrong. One mother reported that, "It took us over 6 years to get an accurate diagnosis even though we were accurately describing and documenting the apparent challenges she faced." When asked how difficult it was to obtain a clear and accurate diagnosis for their child, over two-thirds of parents reported difficulty. One-third categorized it as "very difficult".

"It is still just awful the lack of services that are available for children with mental health concerns. Communities are still very unaware of how to accept children with mental health needs and their families. There is still so much pointing and whispers from other people and even other parents."

Even with a clear diagnosis, being able to find useful information can be tremendously difficult as parents attempt to navigate the children's mental health system, coordinate their child's care and find out the options available to them. When asked how difficult it was to access this information, 40% found it to be very difficult or somewhat difficult. One parent commented, "I have struggled to access the systems and services available. It seems no one willingly shares what's available because there is not enough for everyone. If you're lucky, you just fall upon a service."

Parents were also asked more specifically what additional barriers they confronted in accessing care for their child, independent of cost. They could select more than one answer if more than one barrier existed for them. The number one response was long waits to get an appointment (61%), making it far and away the largest barrier reported by respondents.

⁵ Shonkoff, J. P. & Phillips, D. A. (2000). From Neurons to Neighborhoods: The Science of Early Childhood Development. Washington, DC: National Academies Press.

Parent comments throughout the survey identified delays in access to services as their largest obstacle (35%). Others added that restrictions, such as eligibility for state agency services or limitations on types of treatments covered by private insurance increased delays. 38% of parents reported that their child needed a specific treatment or service that their insurance would not cover. One noted, “In my child’s private insurance plan, there is a large gap between what is theoretically available and what is actually authorized.” A third of respondents found that the providers in their area did not take their insurance, and 26% found that if there were providers in their area that took insurance, they did not serve children.

“Most diagnoses overlap, and it seems that providers and others involved do not see the need to work holistically and communicate with each other.”

Geography presented another barrier. A third of families found that the expertise their child needed was not available in their area, and they were forced to either travel long distances (frequently forcing the parent to take off work or pay for extra gas), or not access the service at all. This was most prevalent in Western Massachusetts, which is more rural and has fewer concentrated resources.

The good news is that many families also reported that the services they finally received were effective. Of the many families who wrote about difficulties with access, 41% described how the services their child received made a difference. One mother was happy to report that “It took a while for my son to get the help and services he needed, but once things fell into place, it got better. I’m very happy with his progress.” Another wrote, “I have had a difficult 10 years raising my son and fighting for the care he deserves, but now he is getting it and I am very pleased so far.”

Coordination of Care

When a child has mental health needs, everyone must be on the same page when it comes to his or her treatment. Often many parties are involved – school staff, primary care physicians, therapists, specialists, various state agencies and family partners, to name a few. Parents and caregivers must manage all these varying parties, which is difficult even when they are on the same page. When they offer conflicting advice and opinions, it can be a formidable obstacle in the treatment of the child.

Of all the barriers to care that the survey asked about, parents reported that the coordination of care was improving. When asked to rate the coordination of their child’s care from poor to excellent, over 70% found their child’s coordination of care to be at least moderate. Almost 40% found it to be from moderately excellent to excellent. Only 20% found it to be somewhat to very poor. Yet, many offered comments noting that their own vigilance had led to improved coordination. “Coordination between outside

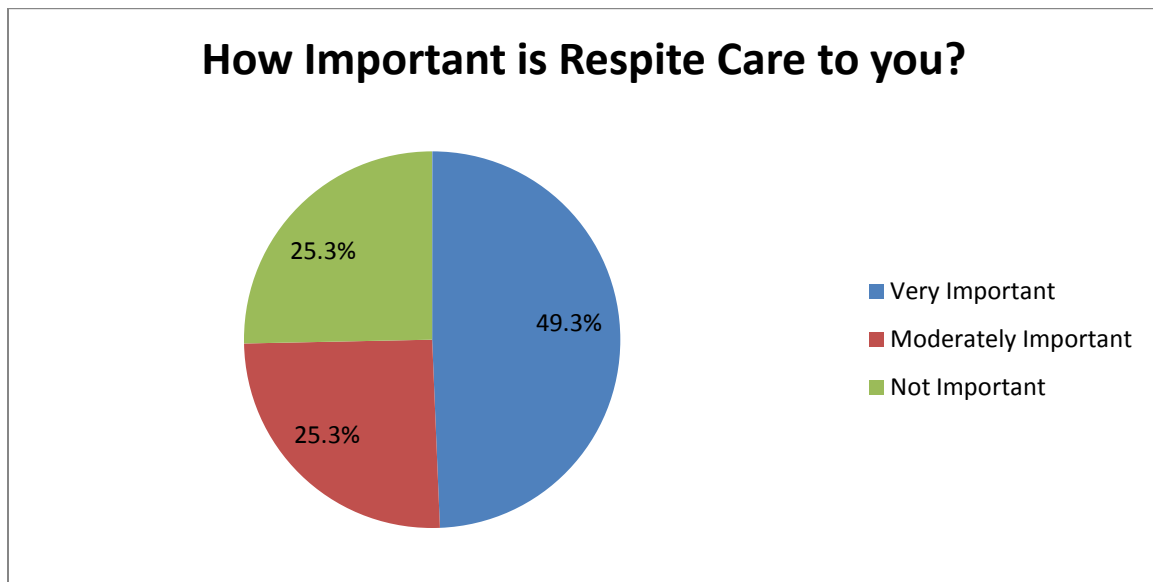
services, which we coordinate ourselves, and the public school system has been spotty at best, despite multiple phone calls and emails.”

Respite Care

Respite care is defined as a “temporary, short-term relief for a family caregiver... provided by a family member, a friend or a paid employee and may involve care of a child or adult with disabilities.”⁶ It is often an essential service for families who need a temporary break from the daily demands of raising a child with significant mental health needs. Respite care has also been shown in studies to help reduce future out of home placements in children, and, with other forms of treatment, help reduce negative behaviors⁷.

“I did not know about it when my children were younger. I would have used it – needed it desperately. My marriage did not survive.”

Although respite care has been shown to be a key component in the overall treatment of children with mental health needs, many respondents to the survey were unaware that such services existed. 19% of parents and guardians who left comments in this section had no knowledge of respite. One even asked, “What is respite care?”



Another wrote, “I don’t know how to get it or what it is.” Many others expressed a desire to receive respite care. Said one parent, “When I have asked about respite care there never seems to be any funds or places that provide it.”

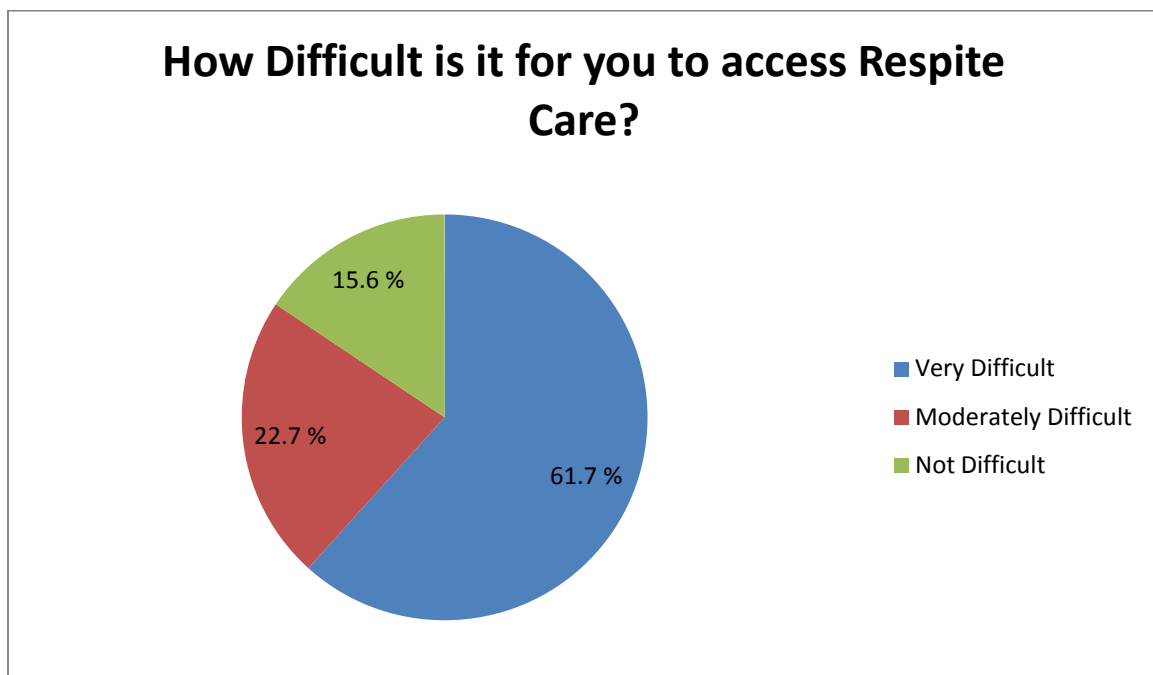
⁶Catalyst Center. Glossary. Retrieve on June 8, 2010. <http://www.hdwg.org/catalyst/glossary/1#letterr>

⁷ Bruns and Burchard study (2000)

This desire is supported by the survey results. When asked how important they thought respite care was to them, parents reported it to be a crucial component in their child’s care. 75% of parents found it to be at least moderately important, and half expressed that it was very important to them. Whether respite care is provided at an out of home facility or with extended family, parents value the opportunity to take a break from the enormous stress of raising their child with mental health needs from time to time.

Although it is looked upon favorably and its importance is appreciated by parents and guardians (even if they elect not to use it), access to quality, timely respite care is limited. Over 60% of those surveyed found it to be very difficult to access. Many parents left comments regarding their difficulty in finding respite. One reported, “I have family members who will take my son from time to time but for the most part we are ALWAYS together.” Some parents tried to access it through various channels only to be put on waitlists or denied altogether. To others, the location was not convenient or was too costly to afford. Many parents did not have family as a fall-back option to take care of their child.

Quality of care from providers was another concern voiced by parents. For those who were able to access respite, they often found it lacking in quality, and came away dissatisfied. Said one parent, “When we tried to access respite services for private pay, we found the provider the agency sent to be dangerously under qualified.” Another parent answered, “Respite providers are not adequately trained to care for adoptive children with Developmental Trauma Disorder due to pre-adoptive histories of severe neglect and abuse.”



Schools

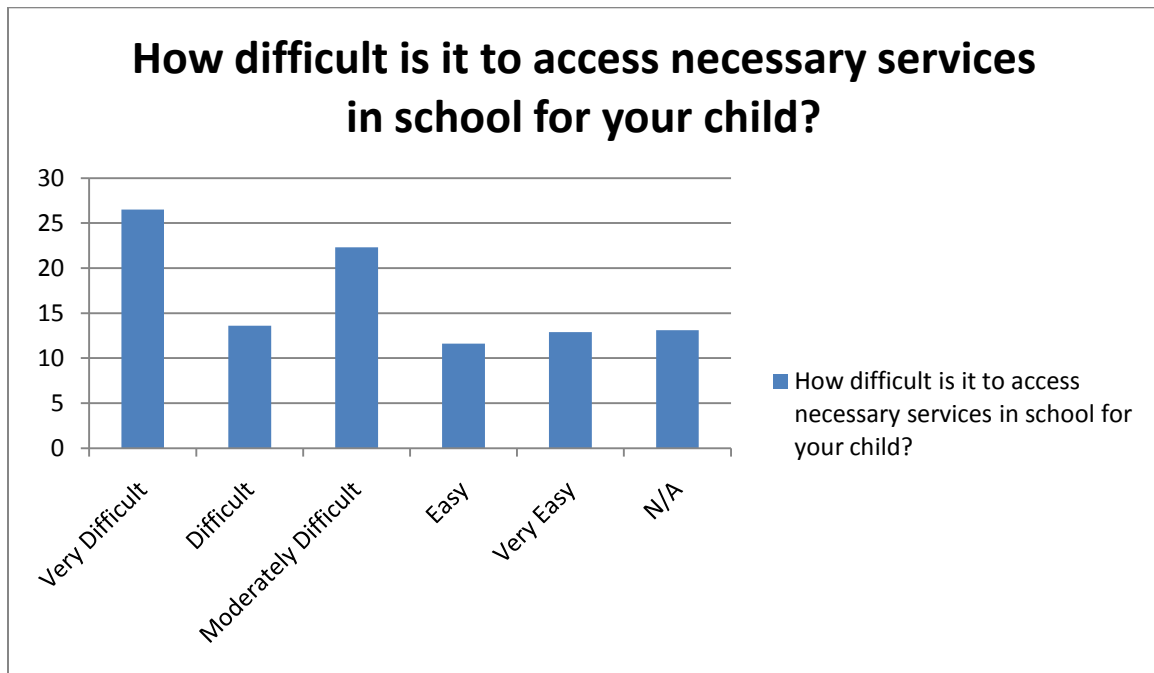
When a child attends school, parents hope they will get the education they need to set an essential foundation for life. The more education a child receives when they are young, the greater their chances are to go to college and make a living in the real world. For children with mental health issues, the obstacles to receiving the education that every child deserves can often be overwhelming and difficult to attain. In order to succeed, these children require adequate services tailored to their specific needs and staff who are on the same page as the family and are receptive and understanding to the child's issues.

“I learned the hard way that while school staff can be a part of the solution, they are neither THE solution nor do they necessarily have the skills or experience to determine what the solution should be.”

Much of the time, schools fall short of their ability to adequately educate and provide services for children with mental health needs. When asked how difficult it was to obtain access to the necessary school services for their children, over 30% found it to be very difficult. Only 28% found it to be moderately to very easy to obtain school services.

When asked how understanding the staff was at the school their child attended, results were mixed.

Approximately 37% of parents believed that staff recognized and understood their child's mental health needs reasonably to very well. Another 25% felt that they moderately understood. However, a third felt that staff were poor to very poor in understanding their son/daughter's needs.



Effective Services

Parents reported that a number of services their child received had made a difference. The treatment parents rated highest was medication (70%), followed closely by therapy (58%). Other highly rated services included school services (54%), social skills groups (33%), out-of-district placements (53%), wraparound services (28%) and parent to parent support (24%).

Even when services matched their child's needs, many parents found they were too short term. One stated, "Each service has been helpful at some point in time. Unfortunately, services don't stay in place either because of funding cuts, child ages out or child does so well they close the case and leave you on your own." An additional 36% of parents reported that they were still looking for effective treatments and services for their child.

Stigma and Impact on the Family

The challenges that parents and guardians raising children with mental health needs experience are considerable and take on many forms. In addition to the many barriers to care parents face, they also face emotional challenges, most notable of which is stigma.

"Epithets were hurled at my daughter from passing cars. I was subjected to harassing anonymous phone calls."

According to an Indiana University study, many misconceptions and generalizations about mental health issues in children abound. They found that 40% of respondents believed children with depression would be dangerous to others and that 31% felt kids with ADHD would also be violent. The study also found that 45% believed that rejection

at school was a likely consequence of a child receiving treatment for their mental health issue⁸.

Parents in our survey were asked about their own experiences with stigma and if it had caused negative outcomes. Almost 70% of respondents reported that their child's behavior was seen as a result of poor parenting. Over half were afraid their child was going to be labeled. 40% felt that their extended family made them and their child feel

⁸ Indiana University study

unwelcome. Said one parent, “We have been ostracized from our community, especially play dates, invitations to birthday parties, etc. Very isolating.”

This stigma is independent of socioeconomic status, geography, or ethnicity. It is a battle that children and families have fought for years, yet have faced bravely and with a determination to promote awareness and acceptance that will someday become the norm.

When parents provided comments on their overall experiences, 24% stressed the impact on their family of both their child’s mental health needs and the challenges in accessing needed services. One stated, “It is a frightening and lonely path that I never envisioned as a parent. Support groups and services are essential. When my daughter suffered her first episode over 3 years ago, I needed to leave my job. Lost wages along with increased expenses has been difficult.”

Other respondents wrote of the impact on their marriages and other children in the family. Others spoke of their differences in parenting styles or stages of acceptance. Many spoke of the need for more public awareness and pointed out the need for educating police and the courts. Each respondent who had received support noted that it made a difference. “All the support I have received has been a lifeline for me,” one wrote.

“We have always had such a huge need for family support services due to having multiple children with diagnoses. Yet, nobody took our needs seriously. When we did finally receive intensive flexible family support, the case manager actually began to cry and stated that she couldn’t believe we were handling so much crisis with no support. It was only then that we began receiving assistance. Before that, we were overwhelmed.”

Helpful Resources

When parents have children with mental health needs, they must navigate a very difficult and complex system. Any time they can receive services and support from others, it goes a long way towards making the journey to treatment a success. Often, parents new to the system find that there is no better resource than other parents who have this experience.

When we asked parents to tell us what the most helpful resource was, they overwhelmingly reported (71%) that it was other parents. Veteran parents have fought the battles and navigated the system and know what works and what doesn’t. One mother wrote, “I am so grateful to be finally connected with our current support group. Our family has been going through exceptionally

difficult times recently and they've been vital in keeping us together and moving in a forward direction."

Many other resources were also helpful to parents. A large number reported that when they sought out information from the internet (58%), attended workshops (58%) and print media (55%), they were able to find the resources they needed, becoming proactive advocates for their child in the process.

Parents also reported that the medical community was immensely helpful as a resource. Two thirds of parents found that their child's therapist was able to assist, with 48% finding that their child's psychiatrist was of help. A little more than a third found the child's pediatrician to be helpful.

There were many other helpful resources that parents found as they navigated the children's mental health system. Slightly less than half of parents (48%), found parent organizations such as PAL to be a helpful resource to them.

Parents value a variety of resources when it comes to making the best, most informed decisions regarding their child. Having other people out there, whether they are other parents, professionals working with children with mental health needs on a regular basis, or family partners, are the best resources. As one parent put it, "the support of other moms like me has been a huge help emotionally."

Conclusion

Families raising children and youth with mental health needs face daunting challenges. They struggle to get a clear diagnosis, understanding that the diagnosis often opens the door to services that match their child's needs. They comb resources online and in a variety of materials in order to find useful information to help them. They wait for extended periods of time, sometimes even years, to access the treatment and services their child requires.

Many families also report that their out of pocket expenses are also challenging. They can be forced to choose between paying other bills, cutting down expenses or delaying other medical care in order to pay for their child's therapy, medications or other necessary treatment. National data shows that they often pay more costs than parents whose children have significant medical disabilities.

Additionally, they encounter a lack of understanding of their child's mental health challenges at every juncture. School staff and extended family alike often blame them for their child's behaviors. As one parent pointed out, "On the one hand, parents are

encouraged and even called neglectful if they don't seek treatment for their children, but then they are accused when the system fails to help and causes even greater harm."

Despite all this, parents wrote again and again how much they appreciated support, excellent resources and effective services. It was striking to note that the most valued resource was another parent, especially one who had already been down the same road. Treatment that positively impacted their child was highly valued. While a hard won success is often sweet, families of children with mental health needs simply want someone to help them identify services that work, ensure that it's affordable and streamline access. That's all any parent wants.