

Findings Brief 2

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Family Experiences with Medication

Over a period of two years, thirty families shared their experiences as they sought services, entered treatment, and remained in or terminated treatment. During those two years, in 13 separate interviews, the parents and caregivers who participated in the study were asked about their experiences with medication.

Psychiatric medication was one of the interventions that many of the children in the study were offered and/or tried. For many families in the study, the child's pediatrician was the first to prescribe psychotropic medication. Most of the children taking medication were prescribed anti-depressants, specifically Selective Serotonin Re-uptake Inhibitors (SSRIs), such as Adderall/Adderall XR, Zoloft, Effexor, Paxil, and Strattera. These agents were prescribed to treat a variety of psychological and behavioral problems, including depression, inattention, and aggression. A few children were taking multiple medications to address a wider variety of symptoms. In addition, most children had tried multiple medications and varied dosages over time, with it proving difficult to find an agent that effectively addressed the intended symptoms without producing intolerable side effects. On page two, Mrs. Brown reports on her son Trevor's — names changed to ensure confidentiality — experiences with medications, which reflect those shared by many families interviewed as part of the study. During this two-year period Mrs. Brown also had another child on a medication regimen.

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Mrs. Brown Reports on Her Son Trevor's Experiences with Medications

Prior to moving to Florida, Trevor, age 16, was seeing a psychiatrist in another state. He had been on and off **Risperdal**. Mrs. Brown reported that her son, Trevor, is very sensitive to medication. She said that his new psychiatrist (private pay) would like to place him on new medication, but Trevor would need to be "detoxed" first, but there are no local hospitals to do this. Trevor has been on **Zoloft**. His dosage was recently increased from 100mg to 150mg. Trevor was also prescribed 200mg of **Welbutrin**. He was "in a trance" so after two days, his dosage of **Zoloft** was decreased to 100mg.

Mrs. Brown reports that Trevor is tolerating the reduced dosage of **Zoloft** so the psychiatrist is rethinking the need to "detox" him. The pharmacy has made repeated errors (dosages) on the prescriptions. Trevor is no longer taking **Ritalin**, because it stopped the normal course of puberty, but they will restart it before school. With the summer here, Mrs. Brown says that Trevor is not taking medications regularly, or is taken reduced dosages, 30mg of **Zoloft**. The psychiatrist (through Children's Medical Services) at the mental health center tells Trevor he may be able to do without the medication.

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Although Trevor's behavior has stabilized, he continues to have problems with bowel obstruction and also reflux issues. Mrs. Brown reports being worried about being able to continue the medication management through the (private pay) psychiatrist, whom she likes and trusts.

Mrs. Brown reports that there has been a very negative change in Trevor's behavior at school and at home. She believes it is a result of his bowel obstruction that has worsened. She is thinking Trevor may benefit from the same type of medication that has helped her and Trevor in the past—**Effexor**. Trevor's medication dosages have increased as a result of his worsened behavior—100mg of **Zoloft** and 75mg of **Effexor**. Mrs. Brown reports that the psychiatrist, before moving to Florida, warned her that these medications lift the levels of some chemicals in the body and may cause some reckless behavior, which Trevor displayed when he was on the combined medications in the past. Mrs. Brown contacts Trevor's old psychiatrist and is told that it is a mistake—the **Zoloft** should be dropped to 25 or 50 mg, not raised to 100mg.

Mrs. Brown reports that Trevor is doing well. She says his behavior is stable and there have been no changes in his medications.

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Trevor was "groggy" in school so his dosage of **Welbutrin** was decreased to 100mg and his dosage of **Zoloft** was increased to 125mg. Mrs. Brown reported that Trevor has side effects from the medication, blocked bowels. He is given **Paxil**, which seems to be related to his loss of control of both kidneys and bowels.

Mrs. Brown reports that Trevor is going through hormonal changes and medication adjustments are necessary. She says Trevor only gets **Ritalin** once a day, except when someone is coming over or they are going out in public, then it's twice a day. There is still some discussion with the psychiatrist about "detoxing" Trevor, although it looks more like they will not because it seems the medication is right now and his behavior is improving. Meanwhile, the psychiatrist at the mental health center decided Trevor did not need **Ritalin** and put him on **Concerta**, saying that it was just as good as **Ritalin**. Trevor's behavior worsens, but the psychiatrist would not listen. He told her not to buy "resold" **Ritalin** at the school. Trevor also tells the doctor that he is much better on the **Ritalin** than the **Concerta**.

Mrs. Brown reports that Trevor continues to have problems with his bowels and reflux issues and is waiting on the results of his colonoscopy. His behavior is stable. Trevor is on **Zoloft**, **Risperdal**, **Welbutrin** and **Ritalin** (no longer **Concerta**).

Mrs. Brown reports that Trevor is no longer taking **Welbutrin** and increased the dosage of **Zoloft**. He is also taking a minimum amount of **Effexor** since he continues to have bowel problems. Trevor's aide in school has also let Mrs. Brown know that she is worried that Trevor is going blind.

Mrs. Brown says she is worried because Trevor has a diagnosis of **Usher's Syndrome (Retinitis)**. She reports Trevor is now on 90mg of **Ritalin** only.

Mrs. Brown reports that Trevor is taking **Risperdal**, **Ritalin** and **Zoloft**. She fears that Trevor may not be eligible for Medicaid when he turns 18 and has no idea how they will pay for his medications. They are not sure if they will be able to continue seeing the private pay psychiatrist. She reports that Trevor continues to have bowel problems and also had a bad cold and cough that wouldn't clear up. Mrs. Brown and the doctor were concerned about putting him on antibiotics, so they gave him a homeopathic remedy and some sinus and allergy medication. Mrs. Brown reports that it interacted with his medications and for four weeks he was "off the wall." She said Trevor was given an antibiotic, his medications reduced during that time, and then returned to previous levels.

Parents expressed numerous concerns about medications. For example, one parent declined to continue pursuing yet another medication because she felt her child was being used as a “guinea pig.” One family experienced a setback when adjusting medications and found that, while the adjustment improved one health problem, it exacerbated another. The longitudinal design of the study, however, also allowed the investigators to see a transformation in outlook among some of the primary caregivers regarding medications as more information was made available to them and their children experienced successes.

Several families had more than one child with special needs receiving pharmacological therapies. For at least four of the families, cost would have been prohibitive were private insurance or public assistance not available to them. Families reported that even with insurance, out-of-pocket medication costs for a single child were between \$200 and \$270 per month. With no insurance available, one parent had to charge medications for two years. Another parent also reported that, while insurance did cover 80% of most medicines, their insurance did not offer any coverage on some very expensive medicines. Financial difficulties were experienced by many of the families with children whose treatment included a program of psychotropic medication.

The degree to which medication was reported to benefit the children in the study varied a great deal. Some caregivers reported that the use of medication resulted in an improved ability on the part of their children to think and reason, a reduction in aggression, and better control over behaviors in general. These benefits translated to functional improvements at home and in school. In contrast, some caregivers reported that medication did not produce any noticeable improvement. At worst, the side effects of the medication outweighed the benefits, with caregivers reporting that their children became overly sedated, hyperactive, suffered cracked lips, or a loss or increase in appetite.

In some instances, caregivers were hesitant to allow their children to be medicated. They expressed concern about the side effects, the lack of data supporting the use of these medications in children, fear based on their lack of knowledge about their child’s potential response, and the number of people prescribing medications for their child. Based on these concerns, a few caregivers routinely started and stopped their children’s medication at will, without consulting the prescribing physician. In addition, not all children received their medication regularly, which may have had an impact on the effectiveness of the medication.

Seven African American and eight Hispanic families participated in the study. While their experiences with medication varied depending on their ethnic/racial background, language proficiency, education, and immigration status and permanency, many of

“We don’t know what we’re doing. We’re just playing with it again. Same as usual.”

“I know what Depicote has done to his teeth and gums. . .that’s the visible, but what’s in there, inside him. . .to me every six months a blood level check is not really good enough to satisfy my fears.”

“I never saw the difference [with the medication] to begin with.”

“He starts this week with a new medication called Strattera. I don’t know anything about the medication. It’s brand new from January. It’s not very well tested, not FDA approved [for children] and it’s for adults. I don’t like the guinea pig feeling. . .”

their experiences mirrored those of other families in the study. For example, Hispanic families had a difficult time giving so many medicines to their children. They were concerned about the side effects, and preferred to stop medicating their children for several months to prevent side effects from being too severe. These changes often took place without prior authorization from the physician.

According to some families, local, state and national policy changes affected the medication issues for the participating families. Aside from the cutbacks in programs that caused interruption of insurance coverage or prescription coverage, one family reported a county policy that required that medications be obtained at a particular pharmacy at the opposite end of the county from where they lived. Another family experienced a delay in receiving prescribed medication because it had to be special-ordered. In the face of uncertainty and limitations of health insurance coverage, some families were forced to delay needed medication for their children.

What the Research Says

Today's treatment for emotional and behavioral disorders in children may combine psychotherapy, supportive services such as special education or social skills training, and pharmacological therapy. Families are often placed in situations where a medication regimen is the recommended treatment for their child. Children are coming into mental health care with prescriptions from their pediatricians and neurologists for various conditions, such as attention deficit hyperactivity disorder (ADHD), depression, and asthma. Treatment plans document psychiatric or psychological assessments that frequently result in a child receiving medication for treatment of a behavioral disorder. Nationally, the total expenditures on psychotropic medications for children in 1998 were estimated to be \$1.1 billion (Ringel & Sturm, 2001).

The Surgeon General's **Supplement to Mental Health (2001)** "...encourages people with mental illness, regardless of race or ethnicity, to take advantage of scientific advances and seek effective pharmacological treatments for mental illness" (pg. 37). Studies show positive benefits of some psychotropic medication being reported by families, with evidence indicating the merit of most of these interventions in treating some behavioral disorders, such as ADHD, when properly used and monitored (Findling et al., 2002). According to some estimates, as many as 80–90% of children and adolescents with ADHD will respond favorably to medication, although the response rate is somewhat lower for preschoolers (Rapport et al., 1994; Hughes et al., 2001). Multimodal treatments, treatments in which pharmacological and psychosocial interventions are used in concert, are also reported to attain positive results with diminished dosage of drug therapy over time (Green, 2001).

Still, there is recent controversy over prescribing psychotropic medications for children as is reflected in current reports and in the literature. For example, the **National Alliance for the Mentally Ill (NAMI)**'s recently released **Report on Children and Psychiatric Medications** recommended making children a priority and that **NIMH (National Institute for Mental Health)** increase research focused on the early onset of mental illness and long-term studies of the use of psychotropic medications in children. NAMI medical director, Dr. Kenneth Duckworth stated,

"Life is uncertain. Risks are real and must be carefully weighed. But sometimes the worst risk lies in doing nothing" (National Alliance for the Mentally Ill press release, 2004).

The President's **New Freedom Commission on Mental Health Report** states,

"Breakthroughs in developing the next generation of medications provide hope for treatment and recovery from mental illness. . . However, since these medications are treatments and not cures, some individuals with chronic illness, including children, are expected to use these medications over an extended period of time. . . long term effects have not been studied well enough for many psychotropic medications" (pg. 70-71).

Greenhill and Associates (2003) identified obstacles and special challenges faced by investigators who conduct psychopharmacological studies in preschoolers. They concluded that with preschoolers being increasingly treated with medication for emotional and behavioral disorders, current and future research must address the safety and efficacy of these psychopharmacological treatments. Many families and treatment providers remain cautious.

Caregivers often express concerns about placing their children on medication. Parents are frightened and unsure of the intended and unintended effects of medication, especially on their younger children. Parents are not comfortable with the current knowledge about psychotropic medications and current choices for treatment (Barrett & Ollendick, 2000; Lazear & Worthington, 2001). Issues with adherence, the extent to which caregivers and children agree with and follow through with the recommendation of the physical or behavioral health care provider, are reflected in the literature. In addition, with health insurance coverage tenuous for many families, parents report struggling to purchase medication prescribed by the child's psychiatrist, and being forced to "stretch" medication over the course of the month to make it last longer (Lazear & Worthington, 2001).

Cultural beliefs about the utilization and effectiveness of medication must also be understood, along with a family's previous experiences with health delivery systems (Canino & Spurlock, 2000). Culture matters because it affects:

- Attitudes and beliefs about mental health;
- The expression of symptoms;
- Coping strategies;
- Help-seeking behaviors;
- Responsiveness to treatment;
- The utilization of services; and,
- The appropriateness of services and supports (Gibbs & Huang, 2001).

There is, however, a lack of research addressing the differences of the effects of psychotropic medication on ethnically, racially, economically, or socially diverse groups of children. There is some data to suggest ethnicity and non-biological factors can affect the response to psychopharmacotherapy — specifically, the non-biological factors that may affect compliance with a medication program, the intensity of the placebo effect, and the reporting of positive or negative effects (Poland & Lin, 1993; Smith et al., 1993). The Surgeon General's Supplement to Mental Health (2001) reports the existence of striking disparities for minorities in mental health care and the underlying knowledge base and reported that minorities do not yet completely share in the hope offered by scientific advances in understanding and treating mental disorders.

Based on the experiences of the families in the study, as well as evidence-based and promising practices the checklist on the following page can help guide the development of systems of care as they address issues of medication. There is a continued need to combat stigma and to develop a targeted education campaign related to research and dissemination of alternatives to medication, as well as utility, risks and safety of medications.

System of Care Checklist: Family Experiences with Medication

- Clinicians individualize therapies, and medication regimens, according to the age, gender, culture, ethnicity, and other life circumstances of the child and family.
- Physicians and health practitioners are aware of and incorporate into treatment the cultural beliefs about mental health, the effectiveness of psychotropic medication, and the use of alternative medicines and folk beliefs for children and youth and their families to whom they provide services.
- Care coordinators are aware of and incorporate into service planning the cultural beliefs about mental health, the effectiveness of psychotropic medication, and the use of alternative medicines and folk beliefs for children and youth and their families to whom they provide services and supports.
- School officials and necessary staff are encouraged to be involved in medication management as they often play a supportive role in helping to detect signs of significant behavioral problems or side effects from medication.
- System of care partners, such as therapists, doctors, case managers and teachers, investigate the rationale behind non-compliance with medication regimens when it occurs.
- Prescribing physicians are aware of the availability of certain prescriptions, and plan temporary remedies when access may be delayed.
- Physicians and other child-serving professionals support parents in making decisions on the use of psychotropic medications through informed consent, based on risks and anticipated benefits.
- Parents are partners in the management of medication prescribed for their children and are kept well informed during the process of identifying the proper medication and dosage, and its effectiveness.
- Families are informed of and understand the right of parental choice, and the right of access to effective treatments.
- Legislators and policy-makers consider the scientific evidence and the needs of children with serious emotional disturbances above the transitory controversies when passing legislation or revising policies.
- A community-based education campaign is on-going to combat stigma and provide education about the utility, risks and safety of psychotropic medications and medication alternatives.

- Pediatricians and specialty mental health providers communicate and coordinate with one another, other necessary team members and the family about the medications they are prescribing to children.

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