

# Medications & Choices: The Perspective of Families and Youth

What Parents and Children Tell Us about Psychiatric Medications

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## Overview

- Changing the conversation about psychotropic medications and families
- What we thought we knew
- Highlights of the parent study
- Highlights of the youth study



## Why we did this



- Trend in prescribing medication includes younger children, 2 or more medications
- Change in public perception
- Trend in questioning whether parents can make optimal choices about medications
- FDA “black box” warnings on certain medications

## Why we did this



- Parents felt vilified by the media, under attack and as if they were not carefully considering their options



## How we did this



- Funded by the Deborah Monroe Noonan Memorial Fund
- This study was family-driven research
  - Families were the source of the questions
  - Focus on how things work in the real world
  - Research is an advocacy tool for change & to improve lives of youth and their families
  - Results were shared with families, general public

## 4 qualifying questions



- Massachusetts resident
- Involved in decision making for child's meds
- Child 19 or younger
- Child must have taken psychotropic medications in last 12 months

## Who were the families and children?



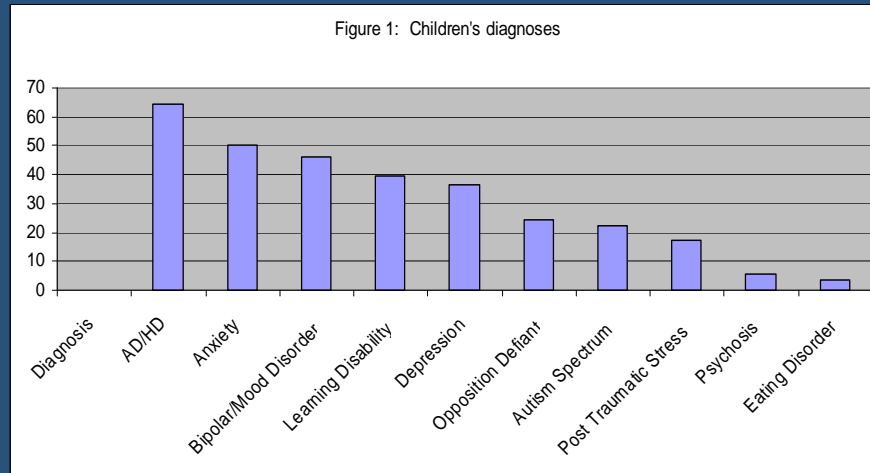
- 302 surveys returned, 274 for analysis
- Involved with PAL, CHADD, Adoptive Families Together, bipolar & Aspergers groups
- Average age 13, 38% were 12 or younger
- Moderate to serious mental health issues (86% in therapy, 81% special education)
- 62% private insurance, 55% Medicaid

## Who were the families & children?



- Most common diagnoses were ADD/ADHD, anxiety, bipolar, learning disability, depression
- Most children diagnosed at young age: 25% received 1<sup>st</sup> diagnosis at age 4 or younger and 50% were diagnoses at 5-9
- More than 50% wrote comments, shared stories, wrote in margins

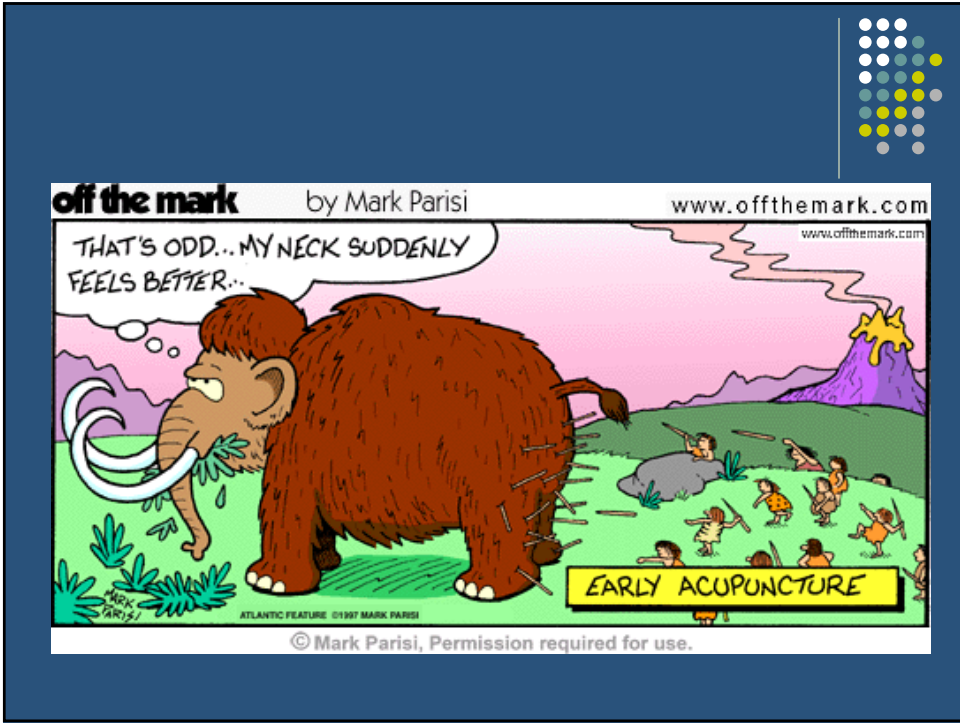
## Diagnoses



## Alternatives to medications

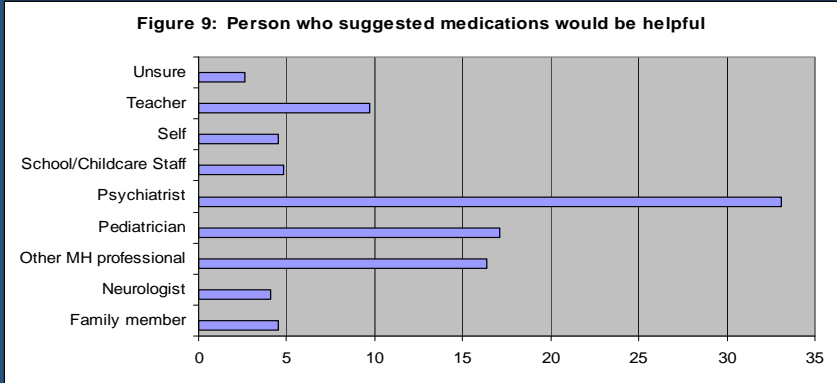


- Parents spoke of their wish for more choices
- 50% tried alternatives before beginning meds
- 44% somewhat effective; 30% not at all
- 82% tried alternative treatments including
  - Behavioral plans (91%)
  - Restricted diet (26%)
  - Exercise, yoga (24%)
  - Herbal remedies (18%)
  - Visualization (16%)



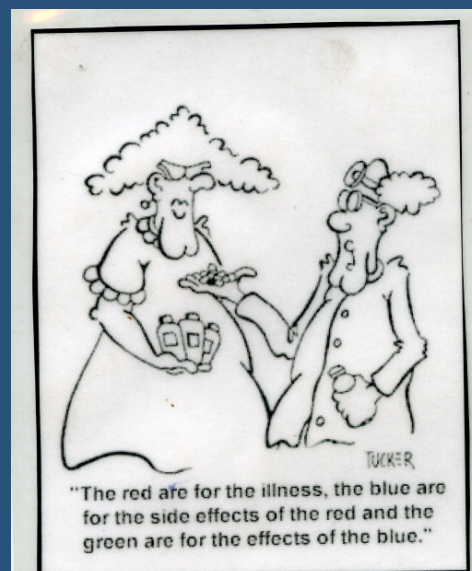
# Medication recommendation

- Less than 5% said they themselves suggested beginning meds



## Medication Trials

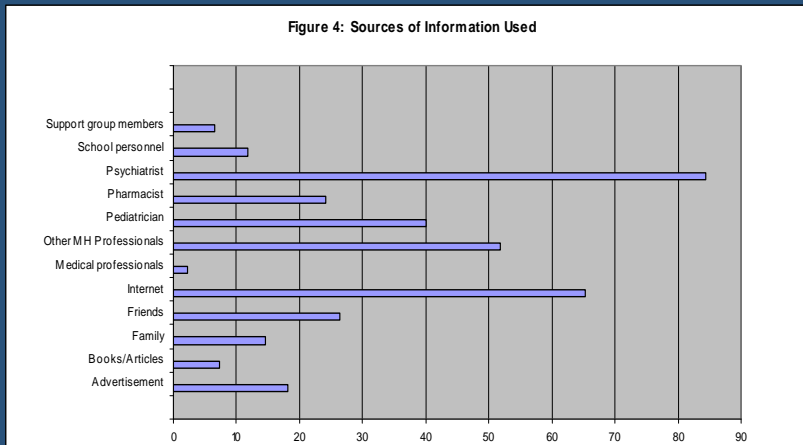
- Single issue generating most comments
- Only 5% reported 1<sup>st</sup> medication worked
- 24% had tried 1-2 medications
- 22% had tried up to 4 medications
- 18% had tried 7 or more
- 57% reported stopping at least 1 medication in previous year
- Side effects most common reason



# Information



- Access to reliable information is crucial for families



# Information



- Child's psychiatrist most reliable source
  - Valued prescriber
  - Good information on dosage, benefits
  - Less satisfied on side effects, interactions
- Most families consulted 2-5 resources
- Only 18% consulted pharmaceutical ads
- Less than 1% found advertisements a good source of knowledge

## Other influences



- Majority (58%) knew of FDA “black box” warnings but said it did not influence them
- If another family member was taking medication, decisions were influenced (56%)
- Insurance coverage influenced decision making:
  - 76% said insurance covered all needed med visits
  - 53% said insurance coverall all needed therapy

## Satisfaction



- Throughout survey parents expressed satisfaction because medications worked
- When other family members took meds, 1.9 times more likely to be satisfied
- Latino families were 3.2 times more likely to be dissatisfied than Caucasian families
- Many also expressed ambivalence at the same time they expressed satisfaction

## Satisfaction



- 90% said medications helped their child deal more effectively with his/her problems
- 86% would recommend medications as an option to a friend
- 74% said they are satisfied with the medications their child takes
- Parents reported satisfaction because medication worked

## Conclusions



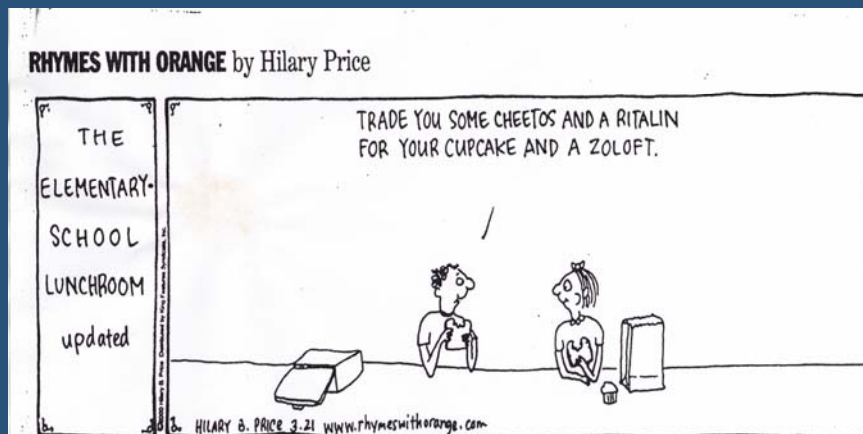
- Parents satisfied but often ambivalent
- Most try alternative treatments
- Most search for useful information
- Valued advice from doctor over federal gov't
- The path to find effective (combination of) medications often difficult
- More than a medical decision – affected entire family

## Making an Impact



- Reviewed by Ben Vitiello, MD at NIMH
- Being used by AACAP in visits to the Hill
- Shared at 2 national conferences
- Will be shared at national school nurses conference in June

## Youth Survey



## Who were the youth?



- Online survey and 3 focus groups
- 86 youth responded, final sample 66
- Ages 10 to 21
- Showed expertise about their bodies and lives
- Knew which meds they were on, which helped, side effects

## Characteristics



- 54% male, 29% female (3 did not answer)
- Average age 15.3 years
- 21% taking 2 medications, 25% took 3, 13% took 6 or more
- Most disliked being on multiple medications

## Side effects, stigma, worries

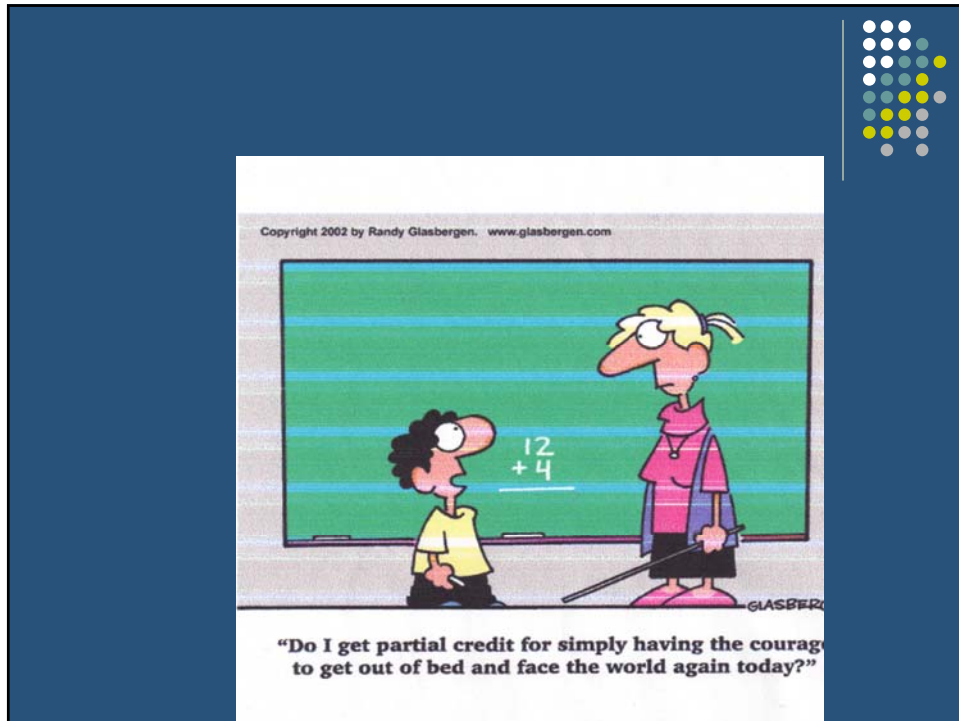


- 61% of youth worried about effect of medication on their bodies today
- Youth focused on side effects interfering with day-to-day life, not long term effects
- Youth felt medications left them open to judgment of others

## Stigma vs privacy



- Youth worried less about stigma, more about privacy
- 49% comfortable telling friends, 51% were not
- Distinction between close friends and peers
- More comfortable letting close friends know they take medications



## Getting information

- 82% got information about medications from doctor, 62% from parents
- Only 5% used internet
- Many youth said parents helped them understand the reason for medications
- When communication by prescriber to parent inadequate, youth do not get needed information

## Getting information



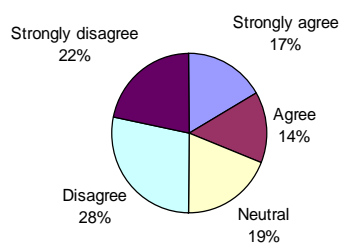
- 70% reported opportunity to ask questions of prescriber, 50% included in decision making
- Many relied on parents to ask questions, only jumping in if something unclear
- 62% felt prescriber explained benefits of medications
- 58% said they were told how specific medications could help

## Information about interactions



- Only 31% said they knew what would happen if they mixed meds with drugs or alcohol

Figure Y-2: The doctor or nurse clearly explains what would happen if I took my medication with drugs or alcohol



## Medications and Schools

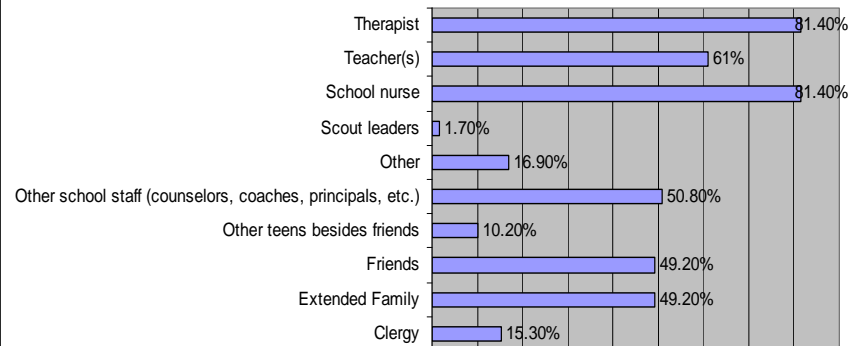


- Most youth preferred taking medications at home instead of school citing privacy.
- Outside of family, youth had highest trust in sharing information about meds with therapist or school nurse

## Comfort sharing information



Figure Y-3: People that youth are comfortable letting know that they take psychotropic medication(s)



## Satisfaction



- 80% reported medications made a positive difference
- Comments focused on help with attention, insomnia
- Even when they dislike medications, admitted that they help when they work

## Conclusions



- Youth more straightforward, less ambivalent than parents
- More concerned with privacy, less concerned with stigma
- Focused on impact today, not future side effects
- Realistic that medications were only part of the answer

## Contact Information



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