Gathering Family Input to Improve Integrated Care

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Overview

- Introduction
- Why we did this: what makes this important?
- How we did this: family driven research
- Who are the families and children?
- Findings
- Key messages and discussion
Introducing Parent/Professional Advocacy League (PPAL)

- A statewide, grassroots, nonprofit, family-run organization.
- Founded in 1991, PPAL is the state organization of the National Federation of Families for Children’s Mental Health and a SAMHSA-funded Statewide Family Network.
- PPAL’s goal is to promote opportunities for families to become strong leaders and to increase and sustain parent and youth involvement at all levels of the system.
- Conducted 10 studies since 2001 to collect data from families

Definition of Integrated Care

**Integrated care** is the seamless provision of health care services, from the perspective of the patient and family, across the entire care continuum. It results from coordinating the efforts of all providers, irrespective of institutional, departmental, or community-based organizational boundaries.

What drove us

- 2009 HRSA funded study of families on elements of medical home and mental health
  - 86% reported they had sole responsibility for coordinating child’s care
  - 59% stated good communication with PCP/specialists increased satisfaction and improved quality of care
  - 51% did not trust school staff with behavioral health information
- SAMHSA funded Statewide Family Network grant
- Affordable care act provides funding for new payment models
- Top 5 out of 6 chronic health issues facing children are behavioral health (JAMA, 2012)
- CHIPRA quality demonstration grant

Our families

- Parents whose children have mental health needs:
  - Highest divorce rate of any group of parents whose children have special needs (Wymbs, et al, 2008)
  - More likely to lose their jobs or live in poverty (National survey of children with special health care needs)
  - Highest rate of out of pocket expenses for needed services
  - Most likely to experience stigma and blame
Family driven research

- Basic principle: Families must be involved in every stage
  - Developing questions, piloting surveys
  - Distributing tool, collecting data
  - Analyzing results
  - Disseminating reports that are family friendly
  - Always thank families
- Partner with others
  - Choose others who value family/youth participation
  - Partners may have questions only families can answer
Family driven research

- Information about families through surveys
  - Ask same demographic questions each time
  - Be prepared for surprises
  - Always ask an open-ended question

- Keep funders interested in your information
  - Gather demographic information that matters
  - Note trends in satisfaction rates
  - Analyze data for specific funders to use in discussions, not reports

How we did this

- 42 question survey plus 1 open ended; 442 responses
- Advisory group; piloted by 3 parents
- Disseminated through family organizations, list serves, social media
- Weekly raffle of gift card
- Weekly e-news update
  - Raffle winner
  - Survey link
  - Parent quotes

- Responses from 11 states, 92% from MA
Who are the families?

- 58.4% reported their child had behavioral health needs while 5.6% reported their child had special health care needs.
- 25.2% said their child had BOTH behavioral health and special health care needs.
- 82.4% Caucasian; 8.3% Hispanic; 5.1% African American; remainder Asian, Native American, mixed race
- 50.9% had advocated for child > 10 yrs; 25.7% 7-10 yrs; 23.5% <6 yrs

Who are the children?

- Most children were teens
- Insurance included private (37.2%), Medicaid (37.2%), combination (23.5%). Less than 2% uninsured.
- 53% of children 0-5 yrs were covered by Medicaid; 39% of children 20-26 had private ins.
- Most received care from pediatrician (68.6%) or family medicine (21.1%)
- 92% had seen a BH specialist; 54% had seen a medical specialist in past 12 months
Finding 1: Families bear the primary burden of coordinating care

- 52% said they were on their own.
- 21% were helped by their child’s PCP
- 32% were helped by the mental health specialist
- 15% were helped by the school
- 14% were helped by a family organization
- Only 4% were helped by medical specialist
Reported impact, unnoticed changes

- 21% felt overwhelmed a lot of the time
- 44% were okay sometimes and overwhelmed sometimes
- 33% felt able to take this task on most of the time
- Only 2% said they didn’t coordinate their child’s care
- 34% reported dramatic increase in child’s needs in past 12 months
- 36% reported increased needs of other family members

MA Child Health Quality Coalition Care Coordination Framework

<table>
<thead>
<tr>
<th>Key Elements</th>
<th>Existing</th>
<th>Potl</th>
<th>Gaps</th>
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<tbody>
<tr>
<td>1) Needs assessment, continuing care coord engagement</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>2) Care planning and coordination</td>
<td>3</td>
<td>2</td>
<td></td>
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<tr>
<td>3) Facilitating care transitions</td>
<td>6</td>
<td>4</td>
<td>2</td>
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<tr>
<td>4) Connecting with community resources/schools</td>
<td>2</td>
<td>2</td>
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<tr>
<td>5) Transitioning to adult care</td>
<td>3</td>
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MA Child Health Quality Coalition CC Task Force  Contact: goerges@mhagp.org
Funded by the Centers for Medicare and Medicaid Services (CMS) through grant funds issued pursuant to CHIPRA section 401(d)
Findings

Finding 1: Families bear the primary burden of coordinating care
Finding 2: Referrals matter but often don’t include elements families value

- 64% said their child had been referred to a medical or behavioral health specialist in the last 12 months.
- 43% said their child had been referred to a community resource.
- 30% said it happened ONLY because they requested it.
- For “interactive” referrals, parents chose “understanding the process,” (53%), 2-way communication so that information is accurate (62%) and understanding the process OVER in-person introductions (36%).
Findings

Finding 1: Families bear the primary burden of coordinating care
Finding 2: Referrals matter but often don’t include elements families value
Finding 3: Families want information but it matters who offers it

Information makes a difference

- Although most families (65%) got information from internet many preferred information from family orgs and other “veteran” parents
- In 2012 PPAL study, families reported that good information increased their satisfaction overall
- 28% said up-to-date accurate information contributed to a successful referral
- 40% said they preferred information in BOTH verbal and written form
Findings

Finding 1: Families bear the primary burden of coordinating care
Finding 2: Referrals matter but often don’t include elements families value
Finding 3: Families want information but it matters who offers it
Finding 4: Families are reluctant to share health information with non health providers

Distinction in sharing child’s information with health or non-health provider

- Parents were more likely to want to approve (66%) sharing of behavioral health information than medical information (61%)
- Parents of children 0-5 were most concerned (81%) about approval
- Parents had different levels of comfort depending on type of information

<table>
<thead>
<tr>
<th>Type of Information</th>
<th>Health provider</th>
<th>Non-health provider</th>
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<tbody>
<tr>
<td>Medications</td>
<td>85%</td>
<td>57%</td>
</tr>
<tr>
<td>MH Treatment</td>
<td>66%</td>
<td>48%</td>
</tr>
<tr>
<td>Psych testing</td>
<td>70%</td>
<td>40%</td>
</tr>
<tr>
<td>Clinical notes</td>
<td>53%</td>
<td>15%</td>
</tr>
<tr>
<td>Substance Abuse tx</td>
<td>26%</td>
<td>9%</td>
</tr>
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Sharing information

- African American and Hispanic parents were more likely to want approval before records were released.
- Asian and Caucasian families wanted to be informed.
- Asian (67%) and Hispanic (52%) families were more likely to say they were not comfortable with ANY sharing with non-health providers.

Findings

Finding 1: Families bear the primary burden of coordinating care
Finding 2: Referrals matter but often don’t include elements families value
Finding 3: Families want information but it matters who offers it
Finding 4: Families are reluctant to share health information with non health providers
Finding 5: Communication matters as does the method
Communication: elements

- 86% of parents said communication with their child’s providers was extremely important to them.

- The top 3 things families identified that makes communication clear and effective were
  - Returning calls/emails in a timely fashion
  - Asking for my input
  - Asking for my child’s input

- Asian (67%), African American (47%) and Hispanic (52%) families chose “understanding my culture” as the top choice.

- Parents with children 0-5 said not repeating their story was important to them (67%)

Communication: methods

- Advent of health portals has increased ways to communicate

<table>
<thead>
<tr>
<th>Way to communicate</th>
<th>BH provider</th>
<th>Medical provider</th>
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<tbody>
<tr>
<td>In person</td>
<td>90%</td>
<td>93%</td>
</tr>
<tr>
<td>By phone</td>
<td>85%</td>
<td>90%</td>
</tr>
<tr>
<td>By email</td>
<td>52%</td>
<td>42%</td>
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<tr>
<td>Health care portal</td>
<td>16%</td>
<td>34%</td>
</tr>
<tr>
<td>Fax</td>
<td>22%</td>
<td>27%</td>
</tr>
<tr>
<td>Texting</td>
<td>21%</td>
<td>11%</td>
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Communication: satisfaction

Have communication options changed in past 5 years and do they meet your needs?

Findings

Finding 1: Families bear the primary burden of coordinating care
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Finding 6: Families want a role in integrated care; need it defined and skill building to participate
Family participation in integrated care: gaining knowledge

Families identified 5 top areas of knowledge

- Information to access school supports (65%)
- Information re: mh diagnoses (53%)
- Information re: support and training for parents (51%)
- Knowledge of insurance benefits (46%)
- Knowledge of state agency services (39%)

Family participation in integrated care: gaining skills

- Families identified key skills which have been required to meet needs of their child
  - Learning to speak out and persist (65%)
  - Learning to locate community resources (64%)
  - Learning to communicate effectively with child’s providers (57%)
  - Learning to network with other families/family organizations (42%)

Is learning to locate community resources an important skill to help your child?

<table>
<thead>
<tr>
<th>Age of child</th>
<th>Percent</th>
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<tbody>
<tr>
<td>0-5</td>
<td>40%</td>
</tr>
<tr>
<td>6-11</td>
<td>69%</td>
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<tr>
<td>12-16</td>
<td>64%</td>
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<tr>
<td>17-19</td>
<td>59%</td>
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<tr>
<td>20-26</td>
<td>76%</td>
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Family participation in integrated care: effective sources of skills/knowledge

- Best sources to gain knowledge and skills:
  - Internet (64%)
  - Family organizations (57%)
  - Other parents (44%)
  - Child’s providers (42%)
  - Books, articles, news (26%)
  - Friends and family (34%)

![Sources of information over time](chart.png)

Impact of increased knowledge and skills

- More effective in accessing services (21%)
- More able to find resources (20%)
- More capable of making good decisions to help child/family (19%)
- Feel more hope about child’s future (19%)
Key Messages

- Family organizations provide care coordination which meets the in the “space between” but PCPs don’t routinely refer to them
- Develop tools to increase ability of families to coordinate child’s care and “drive” their child’s care
- Essential to moving toward integrated care
- Increase and track referrals to family organizations and other effective behavioral health community resources
- Incorporate elements such as information and coaching to ensure effective, high-quality referrals
- Increasing parent knowledge and skills provides positive results, though not adherence
Contact information

Parent/Professional Advocacy League
www.ppal.net

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Questions?
References