

UNITED WAY OF CENTRAL WEST VIRGINIA
PARENTS AS TEACHERS PROGRAM &
WEST VIRGINIA HEALTHY KIDS AND FAMILIES
COALITION

REPORT

WHAT TO DO WHEN YOUR CHILD GETS SICK
A PARENT EDUCATION PILOT STUDY

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WHAT TO DO WHEN YOUR CHILD GETS SICK PILOT STUDY

ABSTRACT

This study is based on self-reported data from parents and other caregivers about how they take care of their children's minor medical needs, such as a fever, rash, diarrhea and vomiting. Study participants answered 29 questions in a pre-intervention questionnaire and the same questions six months later following the intervention. The intervention included a visit in the home by a Parents as Teachers (PAT) home visitor. The PAT home visitor gave each participant a free book, *What To Do When Your Child Gets Sick*; reviewed and discussed the book with parents and followed up each month for 5 more months visiting the parent in the home and spending a few minutes discussing the book and its content. Results of the study from the pre- to post- intervention showed that parents (1) were much more likely to first consult a health book rather than going to a health care professional, (2) were more confident in taking care of their children's minor medical needs at home, (3) used fewer emergency room, doctor/clinic services, and hospital services.

INTRODUCTION

The Institute of Medicine (IOM) of the National Academies reports that 90 million American adults have trouble understanding and using health information.¹ Consumer education and health literacy have increasingly become significant components in addressing quality of health care and health outcomes as well as providing an opportunity to save health care dollars. A study by the UCLA/Johnson & Johnson Health Care Institute suggests that Head Start families could reduce their use of emergency departments and clinic visits if provided with an easy-to-read medical reference manual and training in the art of taking care of their children.²

The UCLA/Johnson & Johnson Health Care Institute launched the study in 2001, by distributing the book, *What to Do When Your Child Gets Sick*, to 1,600 families nationwide. The results among those receiving the book were dramatic: Emergency room trips were reduced by nearly half and clinic visits dropped more than a third. That, in turn, led to a

significant drop in the number of days parents missed work and students were kept out of the school.

In 2005, the Parents as Teachers (PAT) Program of United Way of Central West Virginia, the West Virginia Healthy Kids and Families Coalition, and the West Virginia Children's Health Insurance Program worked together to replicate the UCLA/ Johnson & Johnson Health Care Institute project among families served by the Parents As Teachers program in four counties in south central West Virginia: Kanawha, Clay, Boone and Putnam. The project was funded by the Robert Wood Johnson Foundation through the Center for Health Care Strategies and was part of a national project to assess the experiences of Medicaid and CHIP families in receiving health care services.

The project was preceded by in-depth interviews in 2004 of 101 Medicaid and CHIP families asking about their experiences in receiving health care. The interviews showed that while most (94%) families in the four county region had a regular source of care, they tended to use emergency departments for care after-hours and on-weekends. Findings of the study suggested that inappropriate emergency room use could be reduced if families had better access to their own health care providers. It also suggested that parents would be able to do more at home if they had a good source of information. Families, furthermore, said they would welcome more information on taking care of their children.³ Findings from the interviews are available in the 2004 report, *Experiences in Receiving Health Care by West Virginia CHIP and Medicaid Families*. The report is on the world wide web at www.wvhealthykids.org

METHODS

In January and February 2005, nine Parents as Teachers (PAT) staff visited parent in their home and provided them with copies of the book, *What To Do When Your Child Gets Sick*, explained its contents, and suggested ways in which the book might be used. The books were purchased by the State Children's Health Insurance Program and provided free-of-charge to families.

During the same visit, parents or other caregivers were asked to fill out a written survey with 29 questions. The questions followed the model developed by the UCLA/Johnson & Johnson Institute study. Parents were asked about their health care insurance, whom they rely upon to answer health questions, where they go for care, how confident they are in taking care of their children's medical problems at home and their use of health services. The survey also included demographic questions on the families and children. The survey questions are attached to this report.

Over the next six months, PAT staff used their regularly scheduled home visits once a month, to inquire about the use of the book and spent a few minutes reviewing one or more common childhood illnesses and its treatment as described in the book. Parents in the study were required to complete at least five home visits. Parents, who canceled two or more home visits were dropped from the study.

Six months after receiving the book and initial training, parents and caregivers filled out the same questionnaire to determine if anything, had changed in from the pre-to post-intervention period.

The pre-intervention questionnaire was filled out by 128 parents or other caregivers. The post-intervention questionnaire was filled out by 92 parents. Thirty-six (36) parents did not complete the study because (1) they did not complete the required five visits, or (2) they moved out of the area.

All data in this report is based on self-reports by parents and other caregivers. About 30 percent of study participants, who are also members of Carelink Managed Care Organization, gave permission to analyze their claims data for the pre- and post-intervention period. That data will be available in a separate report.

About the Book: *What To Do When Your Child Gets Sick* covers the management of more than 50 common childhood illnesses and health problems. It is written in an easy-to-read and easy-to-understand manner for parents and caregivers of children from birth to 8 years of age. The book features everyday language with numerous illustrations to describe each illness or health problem and to discuss what needs to be done for the child. Some of the illnesses discussed are earache, sore throat, sunburn, diarrhea, and nosebleed. For each condition, the following questions are asked and answered: What is it? What do I see? What can I do at home? When do I call the doctor or nurse? And what else should I know about it?

What To Do When Your Child Gets Sick was written by two nurses, who through experience in caring for children found that with knowledge many of the common childhood illnesses and health problems could be more effectively managed by parents and child caregivers. Both authors have worked for many years with parents and children. They know the questions and concerns that parents have about their children.

About the Authors: Gloria Gilbert Mayer, Ed.D., and Ann Kuklierus are both registered nurses. Both have clinical experience in caring for children in hospitals and other health care settings. They have worked with doctors, specialists and health educators who care for children. They are principals for the Institute for Healthcare Advancement who have published on topics in the healthcare field and consult on healthcare in private practice.

The book is available from the Institute for Healthcare Advancement at www.ih4health.org

RESULTS

Where Parents Go For Advice on Medical Problems Such as Fever

Before the intervention, more than half of all parents reported that they went to a health care professional for answers to medical problems. Health care professionals included doctors, nurses and pharmacists. About 20 percent of parents consulted family members. Only 2.3 percent reported consulting a health care information book. Six months later, on the post-intervention questionnaire, half of all parents reported, that they would first consult a health care book prior to going to the emergency department; or asking a doctor, nurse or pharmacist. Twenty percent said they would first consult family members and the remainder would consult a health care professional.

Where Parents Go for Advice on Rash

On the pre-intervention questionnaire, 69.6 percent of all parents said they would consult a health care professional; 2 percent said they would consult a health care book. On the post-intervention questionnaire, 58 percent of parents said they would first consult the health care book; 23 percent said they would first consult a health care professional.

Where Parents Go for Advice on Diarrhea and Vomiting

For diarrhea and vomiting, 77.3 percent of parent prior to the intervention would first consult a health care professional; 3.9 percent said they would first consult a health book. On the post-intervention questionnaire, 33.7 percent would consult a health care professional, while 50 percent would first consult a health book.

TABLE 1						
	Fever		Rash		Diarrhea/Vomiting	
	Pre	Post	Pre	Post	Pre	Post
Family Member	28.9%	19.6%	28.1%	14.1%	18%	9.8%
Pharmacist	3.9%	1.1%	14.1%	2.2%	2.3%	1.1%
Hospital ER	14.8%	3.3%	7%	3.3%	10.9%	6.5%
Doctor or Clinic	39.1%	12%	43%	12%	56.3%	20.7%
Nurse Advice Line	10.2%	7.6%	5.5%	5.4%	7.8%	5.4%
Health Book	2.3%	50%	1.6%	57.6%	3.9%	50%
Internet	0.8%	0%	0.8%	0%	0.8%	0%

Question: If your child is sick with a problem such as a fever (rash, diarrhea, vomiting) and you do not know what to do, where would you go most often for information?

Confidence of Parents in Taking Care of Illness at Home

The level of confidence parents had in treating a fever at home increased by 16% from 32.8 percent to 48.9 percent of parents feeling totally confident from pre-to-post intervention. Parent confidence in treating a rash increased by 23.8 percent from 24.2 percent to 48 percent feeling totally confident. Their confidence in treating diarrhea or vomiting increased by 25.7 percent from 29.7 to 55.4 percent feeling totally confident in treating a fever at home.

TABLE 2						
	Fever		Rash		Diarrhea/Vomiting	
	PRE/POST		PRE/POST		PRE/Post	
1-3	1.6%	0%	5.4%	0%	1.6%	Check data
4-6	16.4%	3.3%	24.2%	10%	22.6%	Check data
7-9	32.8%	48.9%	45.1%	39%	46.1%	40.2%
10	32.8%	48.9%	24.2%	48%	29.7%	55.4%

QUESTION: How confident are you that you could take care of your child's fever/rash/diarrhea/vomiting at home? The scale ranged from 1-10 with 1 being not confident and 10 being totally confident.

USE OF SERVICES

Parents were asked several questions on their use of health care services including use of emergency department services, doctor or clinic services for sick care, doctor or clinic services for well care, and hospital stays. Use of health care services was reduced for all services from the pre-to-post intervention period except for use of doctor/clinic services for well care. Well-care visits actually increased slightly from the pre-to-post intervention period. When asked initially if they had taken their child or children to the emergency room in the past six months, 37 percent of respondents said "yes," and 63 percent said "no." After the six month post-intervention period, 26.1 percent of respondents said "yes" and 69.6 percent said "no;" and 4.3 percent did not respond to the question.

TABLE 3		
EMERGENCY ROOM USE		
	Pre	Post
No Answer	0%	4.3%
Yes	37%	26.1%
No	63%	69.6%

Question: Did you take your child to an emergency room during the last six (6) months?

TABLE 4						
	Hospital Stays		Doctor/Clinic Use: Sick Care		Doctor/Clinic Use: Well Care	
	Pre	Post	Pre	Post	Pre	Post
Zero	88.2%	93.5%	20.5%	31.5%	16.5%	12%
One	3.1%	3.3%	22.8%	31.5%	60.6%	65.2%
Two	3.1%	2.2%	25.2%	22.8%	11%	12%
Three	0.8%	1.1%	7.1%	6.5%	5.5%	5.4%
Four	1.6%	0%	8.7%	2.2%	3.9%	3.3%
Five	1.6%	0%	1.6%	1.1%	1.6%	1.1%
Six or more times	1.6%	0%	14.2%	4.3%	0.8%	1.1%

Questions: In the last six months, how many days has your child been in the hospital for one night or more? In the last six months, how many times have you taken your child or children to the doctor for sick care? In the last six months, how many times have you taken your child or children to the doctor for well child care or check-up?

ABOUT THE FAMILIES

One hundred and twenty eight families participated in the study. Of that number, 128 filled out the pre-intervention questionnaire and, 92 filled out the post-intervention questionnaire six months after receiving the book and initial training. Information on the pre-intervention questionnaire represents 157 children; the post-intervention questionnaire represents 115 children. Almost all the respondents and primary caretakers of the children were women (98%) and more than 90 percent were white. About two-thirds (66.4%) of the respondents were married. More than two-thirds (74%) had a high school degree or its equivalent. About half the families (48%) earned less than \$20,000 per year.

Almost all families are eager for more information on how to take care of their children. Prior to receiving the book, *What to Do When Your Child Gets Sick*, 86 percent of families thought such a book would be very useful (75%) or somewhat useful (10.9%). After six months of using the book, 92.4 % felt the book was very useful (80.4%) or somewhat useful (12%).

About the Children

The majority of children (76%) in the study were under age six as reported both on the pre-and post-intervention questionnaire. While most children in the study were healthy, a significant percent were reported as having long-term medical problems such as asthma or diabetes. On the pre-intervention questionnaire, 15.7 percent of children were reported as having medical problems; on the post intervention questionnaire, the response was even higher with 25 percent reported as having long-term medical problems.

More than 95 percent of all children were reported as having a regular source of medical care. This finding reflects similar data reported in the 2004 study on West Virginia health care experiences.

Insurance Coverage

While almost all children in the study had health care coverage through Medicaid, WVCHIP or an employer-based plan, about one of in four (24%) of the adults in the study did not have health coverage. The remainder had coverage through Medicaid (36%) or an employer (39%). Families in the study were uninsured at about the same rate as other working-age West Virginians. Because more adults in the study were women, poor and with young children, their Medicaid participation is much higher than would be expected for the working-age population statewide.

Days Work and School Missed Because of Child Illness

The inappropriate use of health care services is not only wasteful of health care resources, but also have economic consequences for the families in terms of work missed and for the children in terms of school missed. On the pre-intervention questionnaire, 128 parents reported having missed a total of 76 days of work because of the illness of a child. On the post-intervention questionnaire, 92 parents reported having missed 41 days of work days per parent because of the illness of a child.

Children also missed school because of illness but no difference in days of school missed was documented from the pre-to post-intervention period. The 157 children represented in the pre-intervention questionnaire had missed 174 days of school in the previous six months or an average of 1.1 days per child. The 115 children represented in the post-intervention questionnaire missed 101 days of school or an average of 1.1 days per child.

CONCLUSIONS AND RECOMMENDATIONS

As states grapple with saving health care dollars in Medicaid and other programs, the experience of providing families with simple, easy-to-understand information about how to take care of minor needs at home and avoid expensive emergency room care or even clinic or doctor care deserves serious consideration.

The data and anecdotal evidence from the study suggest that parents are eager for information and receptive to the approach described in this study. It is important to note that parents received the book and training as part of an on-going relationship with Parents as Teachers home visitors. They were advised, counseled and supported over a period of six months about the use of the book.

We have not attempted to quantify cost savings from this study. The UCLA/ Johnson & Johnson Health Care Institute study predicted that \$200 annually per child could be saved in Medicaid costs associated with unnecessary clinical and emergency room visits. In West Virginia about 200,000 children are enrolled in Medicaid annually. If the state could save \$200 per child by implementing the pilot study, the potential savings would be \$40 million per year. Initial costs of implementing the study for 200,000 children are estimated at \$65 per child or \$13 million.

While saving Medicaid dollars is an important goal, other important goals are also met by the pilot study approach because parents are empowered and children receive a better quality of care.

Recommendations:

- Continue pilot studies documenting the impact of a parent education and support approach using the book *What to Do When Your Child Gets Sick*. Try other, less intensive approaches, to see if results are the same or similar.

- Test results from the self-reported data by analyzing actual claims data for families in the six months prior to the intervention, for the six months during the intervention, and for six months after conclusion of the intervention.

¹ Guide to Health Literacy: A Prescription to End Confusion, April 2004

² Ariella D. Herman, PhD; Gloria G. Mayer, RN, EdD, FAAN, Reducing the Use of Emergency Medical Resources Among Head Start Families: A Pilot Study, *Journal of Community Health*, Vol. 29, No. 3, June 2004

³ Experiences in Receiving Health Care by West Virginia CHIP and Medicaid Families, October 2004.

ACKNOWLEDGEMENTS

We are grateful to the families who participated in this study and their willingness to share their experiences in receiving health care for their children. They have a commitment to being good parents and doing the best for their children and deserve the information and support they need to raise bright and healthy children.

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Taking Care of Your Sick Child Project

July 2005

1. What type of insurance does your child or children have?
 - Medicaid
 - CHIP
 - PEIA
 - Private Insurance
 - No Insurance

2. If your child has Medicaid, what is the name of the health plan (HMO) to which your child or children belong?
 - Unicare
 - Carelink
 - The Health Plan
 - Medicaid only; no HMO

3. If your child is sick with a problem such as a fever and you do not know what to do, where would you go most often for information? (Check one box only).
 - Ask a family member
 - Ask a pharmacist
 - Go to the hospital emergency room
 - Go to a doctor or a clinic
 - Call the nurse advice line
 - Look in a health book
 - Go on the internet (the web)

4. If you call the nurse advice line, which line do you call?
 - CHIP
 - CAMC

-
- Unicare
 - Carelink
 - Health Plan
 - Other

5. How confident are you that you could take care of your child's fever at home? (On a scale of 1 to 10 with 1 being not confident, and 10 being totally confident, circle the number that matches how confident you are.)

1 2 3 4 5 6 7 8 9 10
Not confident Totally confident

6. If your child is sick with a problem such as a rash and you do not know what to do, where would you go most often for information? (check one box only).

- Ask a family member
- Ask a pharmacist
- Go to the hospital emergency room
- Go to a doctor or a clinic
- Call the nurse advice line
- Look in a health book
- Go on the internet (the web)

7. How confident are you that you could take care of your child's rash at home? (On a scale of 1 to 10 with 1 being not confident, and 10 being totally confident, circle the number that matches how confident you are.)

1 2 3 4 5 6 7 8 9 10
Not confident Totally confident

8. If your child is sick with a problem such as diarrhea and vomiting and you do not know what to do where would you go most often for information? (Check one box only.)

- a. Ask a family member
- b. Ask a pharmacist
- c. Go to the hospital emergency room

-
- d. Go to a doctor or a clinic
 - e. Call the nurse advice line
 - f. Look in a health book
 - g. Go on the internet (the web)

9. How confident are you that you could take care of your child's diarrhea and vomiting at home? (On a scale of 1 to 10 with 1 being not confident, and 10 being totally confident, circle the number that matches how confident you are.)

1 2 3 4 5 6 7 8 9 10
Not confident Totally confident

10. How many children under six years of age are in your household?

0 1 2 3 4 more than 4

11. How would you rate the care that your child or children receive from your doctor?

- a. Excellent
- b. Very good
- c. Good
- d. Fair
- e. Poor

12. Did you call the Nurse Advice Line with a concern or question about your child during the last six (6) months?

- Yes
- No
- I don't have a nurse advice line

13. Did you take your child or children to an emergency room during the last six (6) months?

- Yes
- No

14. How useful would you find a book that telld you the steps to take in dealing with a child who is sick (such as fever, rash or vomiting and diarrhea)? On a scale of 1 to 5 with 1 being very useful and 5 being not at all useful, circle the number that matches how useful a book would be to you.

1 2 3 4 5
Very useful somewhat useful useful not very useful not at all useful

15. Does your child or children have a regular doctor or clinic?

- Yes
- No

16. Does your child or children have a long-term medical problem (such as asthma or diabetes)?

- Yes
- No

17. In the last (6) six months, how many days has your child been in the hospital for one night or more? (Circle the number of days.)

0 1 2 3 4 5 6 or more

18. In the last six (6) six months how many times have you taken your child or children to the doctor for sick care? (Circle the number of times)

0 1 2 3 4 5 6 or more

19. In the last (6) six months how many times have you taken your child or children to the doctor for well child care or check-up? (Circle the number of times)

0 1 2 3 4 5 6 or more

20. In the last six months, how many days of school (including Head Start or Pre-School) has your child or children missed because they were sick? Circle the number of days.

0 1 2 3 4 5 6 or more

21. If you work outside the home, how many days of work have you missed in the last six months because your child was sick? (Circle the number of days;

0 1 2 3 4 5 6 or more

The following questions are about you and your household.

22. How do you describe yourself – marital status

- Married
- Separated
- Divorced
- Widowed
- Single (never married)

23. How do you describe yourself - race

- Anglo (White)
- Latino
- African-American
- Asian
- Other

24. How many years of formal schooling have you completed?

- 0-8 years
- 9-12 years
- Graduated from high school
- Some college (but did not graduate)

-
- Graduated from college

25. Are you the parent, guardian or usual care giver for the child or children in the home?

- Yes
- No

26. What is your age? (circle the correct one)

18-22 23-28 29-33 34-38 39- 44 45-60 61 or older

27. What is your sex?

- Male
- Female

28. What is your household income?

- Less than \$10,000 per year
- \$10,000 to \$20,000 per year
- \$20,000 to \$30,000 per year
- More than \$30,000 per year

29. What kind of health insurance do you have?

- Medicaid
- Medicare (for people over age 65)
- Private Insurance through my employer
- Private Insurance that I purchase
- I don't have health insurance

RETURN TO:

Revised on 1/9/05