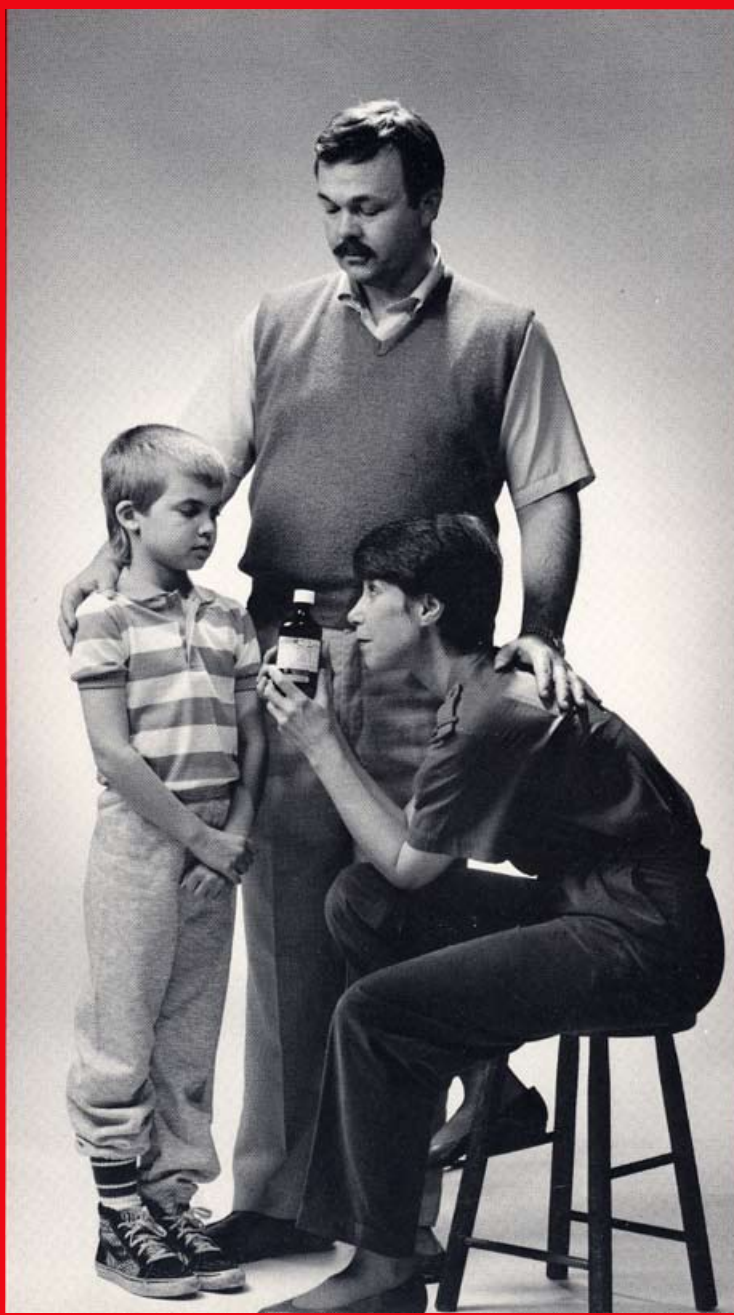


CHILDREN AND AMERICA'S OTHER DRUG PROBLEM:

Guidelines for Improving Prescription Medicine Use Among Children and Teenagers



A Report of
The National Council on
Patient Information and
Education

May 2, 1989

Hon. Paul G. Rogers,
Chairman

Robert M. Bachman,
Executive Director

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Foreward:

This report is offered as a resource for organizations with an interest in issues related to medication use and/or a mandate to serve or represent children and teenagers. The National Council on Patient Information and Education, with the advice of reviewers and our Board of Directors*, developed this report as part of the process of planning a national education campaign to improve prescription drug use among children and teenagers.

The Council wants to share the results of this planning process because the issues and opportunities identified deserve and require broad attention.

* * *

The National Council on Patient Information and Education (NCPIE), organized in October, 1982, is a non-profit organization concerned with improving communication between patients and health care professionals about prescription medicines. NCPIE focuses on a single goal -- to promote the safe and effective use of prescription medicines. Our 247 member organizations represent consumers, health care professionals, voluntary health agencies, government, pharmaceutical manufacturers and other health-related groups. Membership in NCPIE is open to national, state and local organizations interested in patient education issues about prescription medicines. Annual membership dues are \$100.

*Appendix A lists the reviewers, Appendix B lists the NCPIE Board of Directors

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EXECUTIVE SUMMARY

Taken correctly, medicines make an important contribution to the health and quality of life of American children. Unfortunately, however, many American children are not taking (or being given) their medicines properly.

Improper Medicine Use Among Children Is a Widespread Problem.

Studies show that children of all ages take both a large volume and a wide variety of medicines. More than 6 million children have chronic diseases that require regular medication. About 13 million children take prescription medicines in any 2-week period, according to the National Center for Health Statistics. Children also take a substantial number of over-the-counter medicines.

Unfortunately, however, up to half of children who take medicines are not using them properly. In 10 studies of children's medicine use, the average rate of adherence with the regimen was only 54%, similar to that of the general population. The tendency towards not following treatment guidelines holds true even when the medicine is for serious illnesses such as cancer and kidney transplants. Although problems exist among children of all ages, adolescents are even more likely not to take medicine as prescribed than children under age 13.

Four Types of Improper Medicine Use Commonly Occur.

- **Stopping A Medicine Too Soon.**

Although it is important to complete a full course of medicine treatment, a frequent error is to stop giving medicine as soon as the child feels better. A common example is not giving a full course of an antibiotic for an infection. Anti-convulsant medicines also have a history of premature discontinuation.

- **Not Taking Enough Of A Medicine.**

To be fully effective, all the doses of a medicines need to be taken regularly and on time. Yet many doses for children are forgotten, skipped, or given at the wrong times. Sometimes they get the wrong amount of liquid medicines because of improper measurement.

- **Refusing To Take A Medicine.**

Despite potential benefits, many children and their parents don't like the idea of taking medicines. Sometimes the child refuses because of taste or side effects. Sometimes the child's behavior is a covert expression of parental resistance.

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- **Taking Too Much Of A Medicine.**

Overmedication can be dangerous, yet taking a larger dose or more doses than recommended is a common mistake. Problems also occur when parents give over-the-counter medicines, such as laxatives and aspirin, when children are well, as "prevention." The potential for overdose is a special concern because children's physical response to some medicines is more sensitive than that of adults.

The Consequences of Improper Medicine Use Are Serious.

- **Dangerous Health Outcomes.**

When children use medicines improperly, lives are lost, treatable chronic diseases remain uncontrolled, and acute illnesses needlessly continue or recur. For example, improper use has been associated with such results as decreased survival in children with serious diseases such as cancer and decreased function or failure of pediatric renal transplants. Without proper medicine use, children with epilepsy continue to have seizures and diabetes, asthma, and juvenile arthritis can remain uncontrolled. Curable illnesses such as infections do not get better, and resistant strains of bacteria may develop.

- **Inadvertent Treatment Errors.**

When a medicine does not produce the desired result, the physician may assume that the treatment is ineffective. He or she may change a correct treatment approach without realizing that the medicine has not been taken in the right amounts or at the right times. An overdose of some sensitive medicines may result if the physician decides to increase the dose, especially if the child now begins to receive the medicine regularly.

- **Life-threatening Adverse Effects.**

Sometimes errors in prescribing or taking medicines lead to hospitalization and even death for children. For example, stopping adrenocorticoids (cortisone-like medicines that are used for severe allergies, skin problems, asthma, and arthritis) suddenly can cause difficulties in breathing and loss of consciousness. Overdose is another concern.

- **Unpleasant Side Effects.**

Avoidable side effects are most often the result of giving more medicine than prescribed or needed. Diarrhea, other stomach complaints, and skin rashes, for example, can result when children receive too much of an oral antibiotic.

- **Unnecessary Diagnostic and Treatment Costs.**

These include the costs of unused medicines, unnecessary visits and revisits to doctors and hospitals, and higher resulting insurance premiums and health care costs.

- **Greater Risk of Accidental Poisoning.**

As unused medicines accumulate around the house, accidental ingestion by small children becomes a concern.

Seven Factors Contribute to Improper Medicine Use Among Children

1. **Health professionals, parents, and children do not communicate adequately about medicine use.**

Health professionals often do not provide adequate counseling about use of prescription medicines. Parents frequently fail to ask no questions of the health professional. Studies show that parents often do not understand their child's illness or treatment well enough to follow instructions. In addition, children are rarely involved in receiving information about their treatment.

2. **Parents do not adequately monitor their children's medicine-taking.**

A variety of studies document that children, especially older children, are given significant autonomy in taking their medicines. This autonomy often correlates with poor adherence.

3. **Modern family life hinders safe and effective use of medicines.**

"Busy schedules" are a common reason given for forgetting children's medicine doses. Divorce and disorganized lifestyles also contribute to non-adherence.

4. **Parents and children have negative attitudes about medicines.**

Children don't understand the difference between legitimate medicines and illegal drugs. Parents have a variety of fears such as medicines' being "unnatural" or their child's becoming dependent on the medicine.

5. **Parents are poor role models for medicine use.**

Adults themselves have yet to make proper medication use a health priority. Up to half of adults take medication improperly. They do not have the knowledge, attitudes, or skills required, and they may be inadvertently passing on

negative behaviors to their children.

6. Psycho-social barriers contribute to improper use.

Among younger children, school schedules and early bedtimes most often interfere with a medicine regimen. Adolescents may stop taking medicines with side effects that have a negative impact on their appearance and acceptance by their peer group. Medicine-taking may also become part of developmental conflicts with parents.

7. Schools are inadequately involved in educating and cooperating with parents about medicine use.

Safe and effective medicine use and the positive role medicines play in health are not part of most schools' health education curricula. Cooperation between parents and schools around medicine use is not ideal.

Conclusions And Recommendations

Illegal drug use among children and teenagers has been the focus of many educational campaigns in the United States. However, our focus on this concern has overlooked the nation's other drug problem: the improper use of legally prescribed, legally dispensed prescription medicines.

This issue concerns all who care for children: parents, grandparents, and other caretakers of children; health professionals; teachers; and schools. It is a problem for children of all ages, in all parts of the country, of every ethnic and socioeconomic group. It is a concern for healthy children with periodic acute illnesses as well as for children with severe chronic disease.

This report is the National Council on Patient Information and Education's first step in focusing increased attention on this serious problem. Developed by reviewing the professional literature on the topic, it synthesizes what we currently know about improper medicine use, its causes, and its consequences for children and teenagers under age 18. The report also suggests areas where further research is needed, and closes with recommendations and guidelines for reducing the problem.

Our review of the issues emphasizes prescription drug use. However, we recognize that children's use and understanding of prescription and over-the-counter medicines are closely intertwined. Therefore our recommendations relate to both types of medicine. We hope that by alerting the public to this problem now, and by working together, this critical children's health problem can be solved.

Recommendations

1. Improve communication among health care professionals, parents and children about the safe and effective use of medicines.

Studies show that effective patient-professional communication about medicines improves compliance with therapy. There is also some evidence that children can be a productive part of this interchange. NCPIE has adopted this goal as a major priority, and we are developing a national campaign to encourage parents, health care professionals and children to "Speak Up For Children: Talk About Prescriptions."

The final section of our Report suggests "Guidelines for Action" for each of the groups that can help to solve this problem. We urge organizations to use the guidelines to develop activities that enhance communication about medicines and their safe and effective use.

2. Raise awareness among health professionals of the need to educate children, their parents, and caregivers more effectively about how to use medicines properly.

Before parents can administer medicines properly, they need complete instructions such as how much to give, when to give it, and for how long. They need to understand the

benefits of following the treatment as prescribed, the potential consequences of failing to do so, and how to overcome barriers that might occur.

Although many health professionals provide some instructions for medicine use, thorough and effective medication counseling needs to become a medical priority.

3. Urge adult Americans to become good role models for taking medicines safely and effectively.

By setting a good example for proper medicine use, parents can teach their children a health habit with life-long importance. Adults should make proper medication-taking, including active communication with health professionals, a family priority, a cornerstone of good health like a proper diet, exercise, and good hygiene. Parents and children will both benefit from better communication with health professionals about medicines and from following the treatment plan as prescribed.

4. Work with the media to raise awareness of the need to improve prescription medicine use among children.

As a group with significant influence on health awareness, television, radio, newspapers and magazines have an opportunity to bring this issue to the public's attention.

Their efforts can be directly responsible for improving the health and quality of life of American children.

5. Commission research on effective communication about medicines among health professionals, parents, children, and schools.

Research conducted to date has identified a substantial communications gap among those involved in prescribing, administering, supervising, and taking medicines. Studies have also validated effective general communications techniques for improving adherence. Yet a number of issues specific to children's medicine use need further investigation. These include issues such as how to motivate health professionals to communicate about medicines with children and parents, effective techniques for different health professionals in communicating about medicines with children; how to create successful parent-child-caretaker partnerships in proper medicine use; how to improve parental monitoring of children's medicine-taking; effective techniques for working constructively with teenagers to overcome psycho-social barriers to medicine use; and the role of schools in improving medicine use.

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May 2, 1989

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IMPROPER USE OF MEDICINE AMONG CHILDREN IS A WIDESPREAD PROBLEM

Ensuring children's proper use of their medicines is a serious concern for public health professionals and medical practitioners. The size and breadth of the population under age 18 who take medicines and the extent of improper use are compelling reasons for attention.

Children's Use of Medicines Is High

Studies show that children take both a large volume and a wide variety of medicines.^{1,2,3} According to the National Center for Health Statistics, for example, about 40 million children took a medication or a vitamin/mineral supplement in any 2-week period in 1981. About 13 million or 33% of them were taking products prescribed or recommended by a physician. Physicians prescribed two or more medications for 2 million of them.⁴ As Figure 1 shows, many of the children who take medicines have chronic diseases that require regular medication. Overall, however, the most frequently prescribed medicines for children are for short-term conditions (see Figure 2).

FIGURE 1:

More than 6 Million Children Have Chronic Diseases That Require Medicine

Asthma	3,500,000 ⁵
Epilepsy	1,500,000 ^{6*}
Arthritis	165,000 ⁷
Attention Deficit Disorder.....	800,000 ⁸
Diabetes	120,000 ⁹
Cystic Fibrosis	30,000 ¹⁰
Cancer.....	6,600 ^{11**}

FIGURE 2:

What Medicines Are Most Often Prescribed For Children?

Pain remedies	27.8%
Cough & Cold remedies	19.3%
Skin preparations.....	11.3%
Antibiotics.....	5.4%
Allergy medicines.....	4.9%

Source: National Health Interview Survey.¹²

Children also take a substantial number of over-the-counter (OTC) medicines. For example, one study found that 75% of children under age 2 had been given non-prescribed medicine at least once.¹³ In another study, 66% of children ages 2-12 had been given non-

* About three-fourths of the 2 million cases of epilepsy in the U.S. begin before age 21.
 ** Number of cases developed in 1988.

prescription medicine in the last 2 weeks. More than 50% of mothers interviewed kept 5 categories of OTC's on hand for use with children, including analgesics, cough and cold remedies, and dermatologicals.¹⁴

It is also important to note that children of all ages take medicines. Young children, especially those 7 to 12 months old^{15,16} use more medicine than other age groups, mostly for infections. Older children, ages 12-17,^{17,18} also use a substantial number of medicines, but they are more likely to be trying to control a chronic disease. The National Health Interview Survey also found seasonal differences in medication use, with somewhat higher use occurring in the January to March quarter than at other times of the year.¹⁹

Improper Use Is Common

Unfortunately, however, a large percentage of the children who take medicines are not using them properly. In 10 studies of children's medicine use, the average percentage of children who adhered to the regimen was only 54%,²⁰ similar to that in the general population. The tendency toward poor compliance holds true even when the medicine is for serious illnesses. In cystic fibrosis, for example, medication treatment significantly influences the quality and length of a patient's life; yet reported compliance is as low as 65%.²¹ Other studies show

adherence rates of only 55% for juvenile rheumatoid arthritis,²² as low as 22% for oral theophylline in chronic asthma,²³ 57% in pediatric renal transplant patients,²⁴ 59% in pediatric cancer,²⁵ and 57% in epilepsy.²⁶

Although problems exist for all ages of children, adolescents are often less likely to follow a regimen than younger children. In a study of childhood cancer patients, for example, compliance in all age groups was about 66%; among adolescents it fell to 41%.²⁷ Among renal transplant patients the majority of non-compliant patients were adolescents,²⁸ and problems with adolescent adherence have also been reported in diabetes, cystic fibrosis, attention deficit disorders and other chronic diseases.

Four Types Of Improper Medicine Use Commonly Occur

Studies show that there are four principal types of improper medicine use among children. These include:

1. Stopping A Medicine Too Soon

A number of studies report the tendency to premature discontinuation of drug therapy. In two clinic studies of short-term medication adherence, for example, only 18% of children were still taking penicillin on the 9th day of their treatment

and only 7% completed the 10 days of therapy.^{29,30} Reports from private practices have featured better results, but in one study only 56% of patients were still taking penicillin on the 9th day.³¹ Anticonvulsant medications for children also have a history of premature discontinuation.³²

2. Not Taking Enough Of A Medicine

Many patients miss doses of their medication because they or their parents forget about the dose. About 60% of parents in one study said they skipped a forgotten dose rather than making it up³³ -- or asking the physician or pharmacist what to do. Dosage frequency and timing appear to be related to adherence. One study found poor compliance among patients required to take theophylline every 8 hours.³⁴ Drugs prescribed in a once-a-day form were well taken, while 4 doses a day produced only 25% adherence.³⁵

Doses in liquid format may also cause problems. Regimens that call for fractions of a spoonful can contribute to uneven medication ingestion, and caretakers often forget to shake bottles of liquid in suspension, altering the concentration of the medicine.³⁶

3. Refusing to Take a Medicine

Children refuse to take medicines for different reasons. Some have

difficulty swallowing pills or capsules. Others object to the taste of medicines,³⁷ and about 40% in one study complained in general about having to take medication at all.³⁸ In some cases side effects cause children to refuse their medicine, while in others the refusal is a covert expression of parental resistance. Often, the child's recalcitrance is part of a larger behavior management problem.³⁹

4. Taking Too Much of A Medicine

Taking more medicine than the physician prescribed or taking doses more frequently than advised is a common error.⁴⁰ For example, more than a third of parents of hyperactive children said they believed they had the physician's permission to increase their child's medicine dose at their discretion. About one fourth of the group said they often gave extra medicine for "special situations" such as going out in the evening.⁴¹ Parental over-treatment in a variety of conditions has been associated with increased risk of adverse drug reaction.⁴²

Overmedication also appears to be an issue relative to nonprescription medicines, with parents exceeding the recommended doses and length of administration.⁴³ Studies have found additionally that some mothers often give OTC's such as laxatives and aspirin when children are well as "prevention". A panel of medical professionals reviewing

mother's medication decisions gave minimal approval to the way mothers used OTC's.⁴⁴

Inadvertent over-dosage is another concern, because children appear to have different absorption, distribution and metabolic rates than adults for some medicines. Although there have not been many studies comparing medication action in children and adults, existing studies point out differences such as the following:

- Infants have increased absorption of some medicines, such as penicillins and corticosteroid creams; and they may have delayed absorption of others, such as phenytoin and rifampicin. In older children, anticonvulsants may be absorbed more readily.
- Antibiotics appear to penetrate the brain in infants more easily than in older patients, and young infants are more sensitive to narcotic medicines as well. Risk of toxicity is increased in young children because of reduced plasma protein binding, which leads to a greater proportion of unbound active drug in the blood stream. Medicines affected include those commonly prescribed for children, such as ampicillin.⁴⁵ Compared to adults, children also have 70% less body fat, which serves as a temporary storage area for medicines. This makes overdosage much more dangerous, because

most of the medicine remains in the bloodstream.⁴⁶

- Infants appear to have limited ability to metabolize and excrete a number of drugs, and thus need a smaller dose of medicines such as phenytoin and the aminoglycosides. In older children, however, medicines such as theophylline seem to be metabolized more rapidly, requiring larger doses.⁴⁷

There is also some evidence that growth-related physical changes also may alter the action of some medicines in adolescents.⁴⁸

The Consequences Of Improper Medicine Use Among Children Are Serious

The improper use of medicines has a number of adverse consequences, ranging in seriousness from annoying to life-threatening. They include:

Dangerous health outcomes

When children use medicines improperly, lives are lost, treatable chronic diseases remain uncontrolled, and acute illnesses needlessly continue or recur.

For example, improper medication use has been associated with many serious outcomes including decreased survival in children with serious illnesses such as cancer⁴⁹ and decreased function or failure of

pediatric renal transplants.⁵⁰ Without proper medicine use children with epilepsy continue to have seizures,⁵¹ and diabetes, asthma, and juvenile arthritis remain uncontrolled. Curable illnesses such as infections do not get better, and resistant strains of bacteria,⁵² may develop.

Inadvertent treatment errors

If a treatment does not produce desired results, physicians may conclude that the therapy is ineffective, when, in fact, not taking the medicine as prescribed has caused the outcome.⁵³ This assumption can have dangerous results for patients taking medicines such as theophylline or phenytoin, which have a narrow margin between an effective dose and a toxic dose. When unrecognized noncompliance leads a physician to increase the dosage of such medicines, overdose can result, especially if compliance suddenly improves.⁵⁴

Some also believe that the physician's expectation of non-adherence in adolescent patients results in a different approach to care for teenagers. Examples include treating hyperthyroidism with surgery rather than medication and administering penicillin with intramuscular, rather than oral, penicillin.⁵⁵

Life-threatening adverse effects

A few studies have shown that up to 4.6% of pediatric hospital admis-

sions are related to medicines, including problems of adverse drug reactions, inappropriate prescribing, and patient noncompliance with instructions. Up to 44.4% of these problems are severe or fatal.^{56,57} For example, the sudden cessation of medicines such as adrenocorticoids can have life-threatening side effects.⁵⁸ Noncompliance resulting from premature discontinuance leading to hospitalization has been highest with antimicrobials and anticonvulsants.⁵⁹ These studies are several years old, and more research is necessary to delineate the extent of life-threatening situations in this country caused by children's medicine misuse.

Unpleasant side effects

Misuse can lead to unpleasant, and frequently avoidable side effects that may prompt parents to discontinue treatment. In a Canadian study, 11.1% of 4244 courses of pediatric drug therapy resulted in adverse symptoms. The most common were: diarrhea, other gastrointestinal complaints, and skin rashes in children given oral antibiotics; and central nervous system stimulation in children receiving oral bronchodilators. The majority were judged preventable if physicians had used a different medicine or lower doses and if parents had not exceeded the dose or frequency prescribed.⁶⁰

Unnecessary diagnostic and treatment costs

Financial costs of poor medication use include the costs of unused medicines, unnecessary diagnostic and treatment costs, more frequent hospitalizations and emergency room visits, and higher resulting insurance premiums and health care expenditures overall.⁶¹

Greater risk of accidental poisoning

Several authors point out that the accumulation of unused medicines due to non-adherence increases the possibility of accidental poisoning, especially in households with young children.^{62,63}

Seven Factors Contribute To Improper Medicine Use Among Children

The National Council on Patient Information and Education has identified seven factors that contribute to improper medication use among children.

1. Parents, Children and Health Professionals Do Not Communicate Adequately About Medicine Use.

Research on child/parent-professional communication is not extensive and focuses primarily on the physician. However, trends in this literature, and extrapolation from studies relating to adult pa-

tient-professional communication, suggest a need for improvement.

In what are viewed as classic studies conducted in the late 1960's, researchers showed that in pediatric visits only 12.6% of the professional's interactions were with children, although 25% of patients were older than age 5. Only 0.8% of child-directed statements, less than two per child visit, were substantive rather than social.⁶⁴ A 1982 study at the University of California found a more encouraging pattern of 45.5% of a visit's communication taking place between doctor and child. But most of the time doctors only obtained information from the child, while they provided information to the parent.⁶⁵

A 1984 survey by the US Food and Drug Administration found that people obtaining medicines for others, such as a parent for a child, tended to ask more questions of the health professional about the regimen than those receiving their own medicines.⁶⁶ The University of California study, however, found that the doctor initiated discussion 1.8 times more often than the parents (and 8.3 times more often than children.)⁶⁷ A 1987 assessment of children's concerns in pediatric visits found that children did not spontaneously participate at all in a doctor's visit. Yet when asked by researchers 92% had questions about treatment or symptoms that had not been addressed in the patient-professional conversations.⁶⁸

Research also suggests that parents need more or better information to follow treatment regimens. It has often been reported that limited or negative patient-professional interactions cause noncompliance and patient dissatisfaction.⁶⁹ Studies at Buffalo Children's Hospital found that parents' understanding of their child's illness and effects of medicines were often inadequate and erroneous.⁷⁰ Another report found that 58% of non-counseled parents made errors in administration of their child's medicine — and 24% of counseled patients did so as well.⁷¹ A review of relevant studies found that 60% of patients misunderstood their prescriptions⁷², while research with parents of asthmatic children found that between one-third and one-half of parents skipped doses that they considered "unnecessary."⁷³

2. Parents Do Not Adequately Monitor Their Children's Medicine-Taking.

Parental involvement is vital in maintaining compliance and in promoting children's safe and effective medicine use. Yet studies show that children, especially older children, have a great deal of autonomy in taking medicines.

A longitudinal study at Georgetown University found that 35.7% of children in grades K-6 said they took medicine without supervision. About 36% said they picked up prescriptions from the pharmacy or

store independently for themselves or a family member, which investigators verified by personally surveying pharmacies and shops in the neighborhood. About 15% of those surveyed reported giving medicine to another child without adult permission. Mothers interviewed in the study said they believed children aged 12 and older could take a medicine like aspirin without adult supervision.⁷⁴

In some cases, older children's autonomy appears to extend to exclusive responsibility for following a prescribed medication regimen. Yet, the impact of an undefined parental role in monitoring medicine regimens is substantial. In a study of adolescent cancer patients, non-compliance was correlated with lack of agreement between parent and child about who was responsible for administering the medicine.⁷⁵ In two studies related to juvenile rheumatoid arthritis, 32% of parents were vague about how they monitored compliance and almost 50% relied on the child's report to assess adherence⁷⁶. In a study of immunosuppressive therapy, every child found to be non-compliant had sole responsibility for taking the medicines properly⁷⁷. Conversely, parental responsibility for administering medication has been associated with greater compliance⁷⁸.

3. Modern Family Life Hinders Safe and Effective Use of Medicines.

The home environment appears to have a substantial effect on medication use. Studies point to the role of social disorganization in non-compliance. This term includes communication problems within the family and parents whose own lives are too disorganized to ensure regular medication-taking. In a study of pediatric cancer patients, the impact of busy modern life appeared to affect medication adherence. "Busy schedules" were parents' most common explanation for missing medicine doses⁷⁹. Researchers in another study identified family disequilibrium, including divorce, as a prime cause of non-adherence⁸⁰.

The impact of daycare, multiple babysitters, and shared custody on medication compliance has not been reported in the literature. It is possible, however, that multiple caretakers may sometimes complicate medication administration and make it more difficult to follow a regimen regularly.

4. Parents and Children Have Negative Attitudes About Medicines.

Both parents and children appear to hold attitudes about medicines that undermine proper use. In a Georgetown University study, children were found to be confused

and misinformed about the difference between legitimate medicines and illegal drugs⁸¹. The widespread anti-drug messages children hear today undoubtedly contribute to this attitude, particularly because school curricula do not include parallel information on the health benefits of properly using legitimate medicines.⁸²

Parents also have a variety of fears and confusion about medicines. In a study of childhood asthma patients, parents agreed with the statement, "the advantages of medicines outweigh the disadvantages." Yet more than 80% also said that children shouldn't be given medicines for long periods of time; more than 40% said long-term medication is unnatural and harmful to children; and 30% thought children's bodies were too small to cope with medicines⁸³. Another study of adolescents with asthma found that a parent's fear of medicines led to complicity with the patient both in noncompliance and in lying to the physician about medicine-taking behavior⁸⁴. Others report that parents see the need to take medicine as confirming their worst fear that their child is "defective." Parents are also concerned that children may become addicted to medicine or will use it as a crutch. Some believe that when parents do not adhere to medication instructions for their children, it may be a covert sign of resistance to medicine use⁸⁵.

5. Parents Are Poor Role Models for Medicine Use.

There is some evidence that children learn or "inherit" medication-taking behavior from their parents, suggesting that poor medication use is being passed on to a new generation.^{86,87} While these associations are not definitive, it is clear that parental behaviors provide an inappropriate role model for safe and effective medicine use. Adults themselves have yet to make proper medication use a health priority.

Although the literature documents a range of influences on children's health behaviors, parents have sole or major responsibility for their children's medicine use. Yet, improper medication use among adults has been well-documented. According to the National Pharmaceutical Council, up to 90% of patients make errors in the way they take their medicines⁸⁸. Medication compliance is estimated at about 50%, and decreases over time in short-term and long-term regimens⁸⁹. Moreover, adults do not appear to communicate well with health professionals to get the information they need about their medicines. In a 1982 survey by the U.S. Food and Drug Administration, for example, 96% of adult respondents asked no questions about their regimens, even though many said they received inadequate information from the physician or pharmacist⁹⁰. Since the caretakers of children do not have the

basic knowledge, attitudes, and skills required for proper medicine use, the extent of medication misuse among children is not surprising.

6. Psycho-social Barriers Contribute to Improper Use.

Both children and adolescents have psycho-social barriers to proper medicine use. For younger children these problems are often associated with their schedules. Studies report difficulties in taking medication at school and during the busy after school period. Children's early bedtimes may complicate a regimen, and children often fall asleep before their dose is scheduled⁹¹. In addition, a child's ability to learn about medicine-taking is defined by his or her level of development, which can be a problem for parents and health professionals in tailoring medication teaching⁹².

Adolescents also have busy schedules, and they may have less privacy and mobility than adults, which can have an adverse impact on compliance. Teenagers, for example, may not be able to leave birth control pills in sight to help them remember the dose; having to take medicine "in public" at school may be another disincentive.⁹³

Other important barriers to proper medication use involve emotional considerations. One critical problem relates to side effects of medication that have a negative impact on

body image, which is so important to adolescents in development. The cosmetic effects of corticosteroid therapy, for example, include obesity, acne, hirsutism, and cushingoid facies. These side effects have been implicated in noncompliance with immunosuppressive therapy in renal transplants among adolescents⁹⁴ and noncompliance in treatment for systemic lupus erythematosus⁹⁵. In one study, adolescent renal transplant patients said that the steroids caused such an alteration in appearance and disruption of their social life that "it was not worth it"⁹⁶.

Other psychological aspects of adolescence have also been related to medication behavior. Teenagers, for example, are developing their sense of identity, and taking medication may be an unwanted reminder that he or she is "different" or "defective" and may be rejected on those grounds⁹⁷. Some, although not all, studies have correlated a low sense of personal worth and noncompliance with treatments for renal disease⁹⁸, juvenile rheumatoid arthritis⁹⁹, epilepsy¹⁰⁰, birth control¹⁰¹, and juvenile diabetes¹⁰².

In addition, teenagers' relationships with their parents appear to affect medication-taking. Adherent adolescents with epilepsy felt that their families were relatively harmonious and accepted the teenager well¹⁰³. Conversely, poorly adherent diabetic girls often had conflicted relationships with their mothers. They expressed their indepen-

dence and denied the possibility of agreeing on issues with their mothers. Mothers of these girls tended to challenge their daughters' independence, point out misbehaviors, and escalate conflicts¹⁰⁴. It has also been shown that the more teenagers have a sense of independence and freedom in daily life, the more likely they are to adhere to medication treatment¹⁰⁵.

7. Schools are Inadequately Involved in Educating and Cooperating With Parents About Medicine Use.

Currently, schools are not as involved as they could be in promoting proper medication use. For example, safe and effective medicine use is not part of most schools' health education curricula. In a study of high school health textbooks, the volume of material on drug abuse was about 10 times that devoted to legitimate medicines. Only 13% of the material on legitimate medicines focused on safe and effective use¹⁰⁶.

It is not surprising, then, that children's knowledge about legitimate medicines is low. In a longitudinal study, even by age 12 or 13 65% of children did not know that whether a pill is big or small does not affect efficacy; 50% did not know that the taste of a medicine is not related to effectiveness¹⁰⁷.

Medication use and monitoring in the school is another relevant issue.

In the longitudinal study mentioned above, 20% of mothers said their children sometimes took medicine to school. On the day of the interview nearly 10% of children said they had medicines with them, including acetaminophen and aspirin, asthma medicine, stimulant medication, allergy medicines, skin preparations and others. More than half the mothers of these children, questioned independently, said their children never took medicine to school¹⁰⁸.

In long-term conditions such as diabetes, asthma, epilepsy, and attention deficit disorders, cooperation among parents, teachers, and in some cases health professionals is important to safe medicine use. Yet a review of treatment for behavior disorders found that parent-school collaboration most often occurs around a stressful event such as an adverse drug reaction. Teachers felt they had inadequate information on drug effects, the treatment regimen, and side effects. While some teachers gave parents feedback on medication effects, no structured procedure helped them report. Although knowledge about school behavior is considered important in diagnosing and treating behavior disorders, teachers reported that they only exchanged feedback with doctors in between 8% and 17% of cases¹⁰⁹.

Conclusions And Recommendations

This report documents a serious public health problem that has immediate consequences for our children today and long-term consequences as they grow into adulthood. The National Council on Patient Information and Education (NCPIE) urges parents, grandparents, caretakers, health care professionals, organizations, the educational system, and the media to take action now to solve this problem. The recommendations that follow suggest ways that those who care for the nation's children can help them to use medicines safely and effectively -- both now and in the future.

1. Improve Communication Among Health Care Professionals, Parents And Children About The Safe And Effective Use Of Medicines.

Studies show that effective patient-professional communication about medicines improves compliance with therapy. There is also some evidence that children can be a productive part of this interchange. NCPIE has adopted this goal as a major priority, and we are developing a national campaign to encourage parents, health care professionals and children to "Speak Up For Children: Talk About Prescriptions."

The final section of our Report suggests "Guidelines for Action" for each of the groups that can help to solve this problem. We urge organizations to use the guidelines to develop activities that enhance communication about medicines and their safe and effective use.

2. Raise Awareness Among Health Professionals Of The Need To Educate Children, Their Parents, And Caregivers More Effectively About How To Use Medicines Properly.

Before parents can administer medicines properly, they need complete instructions such as how much to give, when to give it, and for how long. They need to understand the benefits of following the treatment as prescribed, the potential consequences of failing to do so, and how to overcome barriers that might occur.

Although many health professionals provide some instructions for medicine use, thorough, effective counseling needs to become a medical priority.

3. Urge Adult Americans To Become Good Role Models For Taking Medicines Safely And Effectively.

By setting a good example for proper medicine use, parents can teach their children a health habit with life-long importance. Adults should make proper medication-

taking, including active communication with health professionals, a family priority, a cornerstone of good health like a proper diet, exercise, and good hygiene. Parents and children will both benefit from better communication with health professionals about medicines and from following the treatment plan as prescribed.

4. Work With The Media To Raise Awareness Of The Need To Improve Prescription Medicine Use Among Children.

As a group with significant influence on health awareness, television, radio, newspapers and magazines have an opportunity to bring this issue to the public's attention. Their efforts can be directly responsible for improving the health and quality of life of American children.

5. Commission Research On Effective Communication About Medicines Among Health Professionals, Parents, Children, And Schools.

Research conducted to date has identified a substantial communications gap among those involved in prescribing, administering, supervising, and taking medicines. Studies have also validated effective general communications techniques for improving adherence. Yet a number of issues specific to children's medicine use need further investigation. These include issues such as how to motivate

health professionals to communicate about medicines with children and parents, effective techniques for different health professionals in communicating about medicines with children; how to create successful parent-child-caretaker partnerships in proper medicine use; how to improve parental monitoring of children's medicine-taking; effective techniques for working constructively with teenagers to overcome psycho-social barriers to medicine use; and the role of schools in improving medicine use.

IMPROVING MEDICINE USE AMONG CHILDREN: GUIDELINES FOR ACTION

14

To help all those involved to improve medicine use among children, the National Council on Patient Information and Education (NCPIE) offers the following guidelines. Taking these actions will enhance communications and awareness about how and why to use medicines safely and effectively. They are based on state-of-the-art approaches in patient-professional communication and adherence-promotion.

Improving Medicine Use Among Children: Guidelines For Parents, Grandparents, And Caretakers

1. **Work In Partnership With Your Health Professionals In Taking Responsibility For Your Child's Health.**
 - Be an active participant in the decision to begin or continue use of any medicine. Ask about possible non- drug treatment options.
 - Tell your doctor or pharmacist about other medicines your child is taking, including over-the-counter drugs. This can help prevent drug interactions.
 - Be sure you ask your doctor or pharmacist these 5 key questions about your child's medication:
 1. What is the name of the medicine and what is it supposed to do?
 2. How often do I give the medicine, how much do I give, and for how long?
 3. What foods, beverages, other medicines, or activities should the child avoid while taking the medicine?
 4. What side effects should I watch for?
 5. What written materials on the medicine are available?
- Pay attention to your child's response to the medicine. If you think it is causing side effects, let the doctor know. Don't be afraid of "bothering" the professional: side effects are important information for making treatment decisions.
- Never start, stop, or adjust the dosage of your child's medicine without consulting the doctor.
- Continue your child's medicine as long as the doctor advises. A common mistake is stopping antibiotics, such as those used to treat ear infections, as soon as the child feels better. But the infection may remain or return unless you complete the full course of treatment.

- Follow the behavioral aspects of treatment that help medicines work best. For example, treatment of a child with asthma is compromised if parents continue to smoke around him or her. In attention deficit disorder or hyperactivity, children who need medicine have better results when they continue behavioral therapy while they take the medicine.
- 2. Talk To Your Children About Medicines. Involve Them In Communicating With Health Professionals And Taking Medicines As Prescribed.**
- Talk to your child about the role medicines play in health.
 - a. Lay the groundwork early. Even preschoolers can understand basic concepts.
 - b. Don't just have one conversation with your child. The importance of using medicines safely and effectively should be reinforced frequently.
 - c. Look for "teachable moments." You don't have to talk about medicines only when a sick child is taking them. Scenes on TV or experiences among people you know that relate to medicine use can provide a natural opportunity to discuss the topic.
 - Help your child take an active part in talking with health professionals to learn about medicines.
 - a. Before a pharmacy or doctor's visit, encourage the child to ask questions about the medicine treatment. If your child has a long-term medicine plan, he or she may want to write down questions that come up between visits.
 - b. Ask the child to listen to the professional's instructions about the medicines he or she will be taking.
 - c. Ask the professional to define terms that may be unfamiliar to the child.
 - d. If the professional does not talk directly to the child, involve him or her yourself in the conversation. Ask him how he feels about the treatment plan, if he understands it, or if he has any questions. Make sure he hears the benefits he will receive from taking the medicine.
 - Teach your children the difference between legitimate medicines and illegal drugs. Use only the term "medicines" to talk about legitimate treatment products and use "drugs" to refer to substances of abuse.

- e. Praise the child for his or her active role in the visit.
- Be a good role model. Take your own medicines in a safe and effective way. Demonstrate active communication with the health professionals about medicines. These behaviors will help children develop good health habits now that will last a lifetime. They will also help you get the most from the medicines you take yourself.
 - Decide together which roles you and your child will play in following the treatment plan.
 - Involve your child in solving problems that make it hard to follow the treatment plan.
 - Help children and adolescents overcome psycho-social barriers to taking medicines as prescribed, such as negative peer pressure, concern about side effects that affect their appearance, and parent-teen conflicts.
 - Don't give your children too much responsibility for taking medicines. Even older children and teenagers need parental monitoring and reminders to take their medicines correctly.
- 3. Communicate With School Personnel About Your Child's Medicines.**
- Let the child's teacher and/or school nurse know if your child is taking long-term medicine in case of emergencies.
 - With medicines prescribed for behavioral or learning disorders (such as attention deficit disorder or hyperactivity), involve the child's teacher with the doctor in assessing the need for medicine, the positive effects of medicine prescribed, and side effects that the child may develop.
 - Work with the school nurse to administer medicines that the child needs to take at school. Encourage the nurse to avoid approaches that single out your child as "different."
- 4. Follow Good Medicine Safety Practices.**
- See the doctor regularly if your child is on long-term medication treatment. Prescriptions should not be renewed automatically without periodic check-ups.
 - Don't give over-the-counter drugs as prevention. Aspirin and laxatives, for instance, can both cause health problems when they're used improperly.

- Store medicines out of the reach of small children.
- Remember that safety caps are child resistant, not child proof.
- Don't give a child medicine that was prescribed for someone else or for a prior illness without talking to the doctor.
- Check the expiration date on all medicines before giving them to your child.
- Avoid medical jargon.
- Spend a little time talking about nonmedical topics.
- Remember that 1 in 5 Americans cannot read well enough to understand the instructions on a medicine bottle. Make your instructions simple and specific.
- Provide medication information/instructions early in your discussion to increase recall.

Improving Medicine Use Among Children: Guidelines For All Health Professionals

1. Develop And Practice Good Communications Skills.

The professional who is warm, caring, and sincere generates confidence and trust^{110,111}. Patient satisfaction and compliance appear to be related to positive patient-professional interaction, and non-compliance has been found related to unmet parent expectations of the professional¹¹². The following suggestions for positive communication are based on a review of various investigations^{113,114}.

- Elicit information about patient/parents worries or concerns.
- Be friendly rather than businesslike.

- Use short words and sentences.
- Repeat your instructions to be sure they are understood.

2. Encourage And Enable Children To Be Active Participants In Their Treatment.

The Health PACT Project at the University of Colorado has found that active participants in health visits are more likely to practice positive health habits and a positive attitude toward health care. Their curricula suggest the following steps providers can take to encourage participation in children from pre-school through adolescence¹¹⁵:

- Talk directly to the child in addition to communicating with the parent. The parent will also hear the information you offer the child.

- Explain the benefits to the child and his or her health of taking a medicine.
 - Explain the medical terms you use in words the child can understand.
 - Encourage the child to ask questions.
 - Ask the child to repeat your instructions to show that he understands.
 - Encourage the child to follow through and take the medicines as prescribed.
 - Praise the child for active participation and taking an interest in his health.
3. **Communicate With The Child According To His Or Her Cognitive Level.**
2. Pre-operational (ages 2 to 7). The child can understand words and symbols, but his cognition is egocentric and empirical rather than logical. He can only focus on one idea at a time.
 3. Concrete operational (ages 7 to 11). The child begins to use elementary logic. He can focus on several concepts simultaneously and can understand, for example, that the quantity of a liquid can be the same in bottles of different heights and widths.
 4. Formal operational (ages 11 to adult). The child is capable of abstract thought, can see alternative possibilities in a situation, and can interpret based on his own reasoning.

Applications of Piaget's model to health suggest the following conclusions:

- Cognitive development theory suggests that children's ability to conceptualize about health and illness progresses chronologically through stages, each of which serves as a necessary stepping stone to the next. A model proposed by Piaget¹¹⁶ shows four stages of development:
1. Sensory-motor (birth to age 2). The child experiences his environment in terms of his own physical sensations.
 - In each stage, children can understand treatment concepts more easily than they can comprehend ideas like causation or prevention¹¹⁷.
 - Health concepts for children in the pre-operational stage are very general and superstitious. They often see illness as a punishment for being bad, and can't describe what it is to be healthy¹¹⁸.

- Children at higher cognitive levels can retain more health information; but, even children who don't fully retain the information benefit from the interchange in enhanced self-image and self-efficacy¹¹⁹.
- Children age 7 and older can usually understand that a disease is caused by germs¹²⁰.
- At all stages, being ill does not seem to impede children's understanding or slow cognitive growth¹²¹.
- Check for objectionable side effects and investigate adjusting the dosage or switching the medicine; reassure the child as appropriate.
- Explore fears about the medicine.
- Talk to the child to make sure his or her "refusal" is not a covert expression of parental resistance. Discuss attitudes about medicine use with the parents.
- Counsel parents on effective discipline: avoid punishment or yelling; let the child know that parent and child will stand there until the child swallows the medicine; allow plenty of time.

A self-management model suggests an approach to involving the child in treatment planning and implementation at three different cognitive levels¹²²:

1. At the simplest level, talk to the child directly about treatment instead of just to the parents.
 2. At the intermediate level, get the child's consent to a treatment plan arranged by the professional and the parent.
 3. At a high level, involve the child in determining details of the treatment regimen.
 4. **Help Overcome Refusal To Take Medicines.**
- In severe cases, consider a brief hospitalization to teach adherence skills and behaviors and help the child develop a new, permanent routine.

Improving Medicine Use Among Children: Guidelines For Physicians And Other Prescribers

1. **Motivate Compliance With Medicine Treatment By Specifying The Benefits.**

The Journal of Clinical Psychiatry¹²³ suggests these five steps:

The literature reports good results using verbal discussion and a written handout, "Why Comply?" Benefits of compliance (with treatment

for juvenile rheumatoid arthritis) are emphasized, including: consistent treatment helps the child feel better; the child will have fewer problems or flare-ups and long-term damage can be minimized; you will avoid further tests and treatments that are bothersome and expensive; the doctor can better evaluate therapy; you may avoid additional medicines¹²⁴.

2. Take Proactive, Concrete Steps To Promote Compliance.

The following action steps reflect current recommendations of compliance specialists^{125,126,127,128}:

- Determine the behavioral goals of treatment.
- Explain the problem and treatment recommendations clearly to the parent and child. Give the answers to NCPIC's five questions:
 1. The name of the medicine and what it is supposed to do.
 2. How often to take it and for how long.
 3. Side effects and what to do if they occur.
 4. Foods, beverages, other medicines and activities to avoid while taking a medication.
 5. What written materials are available for further information.
- Probe for questions and problems that might be encountered in following the regimen.
- Have parents and child develop a plan to overcome identified barriers to adherence.
- Simplify the regimen as much as possible.
- Negotiate the treatment schedule. Tailor the regimen to patient's/parents' lifestyle and routines.
- Use regimen checklists for each patient/parent to note the current regimen and changes over time.
- Give emphatic, structured, explicit, oral, and written instructions.
- Use audiovisual aids to supplement face-to-face counseling. They can be an effective and efficient way to educate patients.
- Model and have patients/parents rehearse following the regimen. Give corrective feedback as needed.
- Negotiate the use of cues and reminders, such as having parents post the written instructions prominently at home, medica-

- tion calendars, or special medication packaging that can make it easier to adhere to treatment.
 - Gradually implement complex regimens in a step-by-step fashion.
 - Agree on parent and child roles in treatment administration and monitoring.
 - Determine new skills needed by parent or child
 - Use reinforcement techniques, including positive feedback, and possibly token rewards for the child.
 - Provide increased supervision by phone and in office\ visits.
 - Ask for a restatement of your instructions and provide written directions to take home.
 - Do not ask patients to do things you would not do yourself.
 - Encourage a health care team approach to medication information. Urge patients to communicate with their pharmacists, for example.
- 3. Before Prescribing Any Medicines To Treat Behavioral And Learning Disorders, Conduct A Thorough Assessment Of The Child's Behavior, School Performance, And Family Interactions.**
- Involve parents and teachers in your evaluation.
 - Try behavioral and/or educational therapy before adding medicines.
 - If you do prescribe medicine, advise parents to continue behavioral or educational therapy. This combination produces better outcomes than medicine alone¹²⁹.

Improving Medicine Use Among Children: Guidelines For Pharmacists

- 1. Develop And Publicize Special Pharmacy Services For Pediatric Patients.**
 - 2. Counsel Parents And Children About Concerns With Children's Medicines.**
- Counsel the child directly to promote adherence. The parent who is with the child will also hear your message.
 - Reinforce the need to complete medication therapy.
 - Advise on OTC use.
 - Emphasize the importance of following the regimen and avoiding dangerous overmedication. Counsel about how to handle missed doses.

- Help parents and children handle difficulties in swallowing medicines.
3. **Work With Parents And Children To Identify And Overcome Barriers To Proper Medicine Use.**
 - Suggest repackaging medicines to help parents monitor whether the full daily dose has been given.
 - Address safe medicine storage issues.
 4. **Develop Monitoring Practices That Support Adherence, Such As Tracking And Counseling For Refills.**
 - Confirm dose requested on sensitive medicines such as those with a narrow therapeutic range and/or a high danger of overdose.
 - Develop medication profiles on pediatric patients to avoid interactions.
 - Assist in follow-up with medication renewals for chronic disease patients. Monitor for renewals and to ensure that regular physician visits are occurring between renewals.
 - Question "automatic" renewals, and counsel parents on the need for regular reevaluation in chronic conditions.

5. **Become Involved In Community Education About Safe And Effective Children's Medicine Use.**

The Iowa Pharmacy Foundation, for example, sponsors the "Katy's Kids" program. It includes an outline and a speech pharmacists can give, access to slides and visuals, and materials for children on responsible medicine use. For more information, contact:

Christopher Decker
Associate Director
Iowa Pharmacy Foundation
8515 Douglas, Suite 16
Des Moines, IA 50322
(512) 270-0713

- Volunteer to assist schools in presenting programs on this topic.

Improving Medicine Use Among Children: Guidelines For Nurses

1. **Assist In Counseling Parents And Children About Medicine Use.**

Nurses in pediatric settings have opportunities for extensive interactions with parents and children. They can provide or reinforce specific advice and guidelines on medication use¹³⁰.

2. Assist In Monitoring And Follow-up.

Give reminder phone calls and review adherence to the medication regimen. The literature suggests that nurses may have a special role with adolescents, who may be more receptive to professional than parental supervision¹³¹.

3. Educate Children To Be Wise Medicine Consumers.

For example, a program at the University of Colorado, Participatory and Assertive Consumer Training, teaches children to become active partners in their healthcare. PACT helps children:

- Talk to the health professional
- Listen and learn from the professional
- Ask questions of the professional
- Decide with the professional what to do about a health problem or how to meet a treatment goal
- Do what was decided¹³².

For further information, contact:

Judith B. Igoe, Director
School Health Programs
University of Colorado
Health Services Center
Denver, CO 80262
(303) 270-7435

Improving Medicine Use Among Children: Guidelines For Schools

1. Include The Role Of Medicines In Health And Safe And Effective Medicine Use In The Existing School Health Curriculum.

- Review and consider using "Teaching About Drugs: A Curriculum Guide K-12." This guide helps teachers present correct information about medicines. It includes learning objectives, content, activities, and supporting resources. "Teaching About Drugs" was developed jointly by the American School Health Association and the Pharmaceutical Manufacturers Association. For further information, contact:

American School
Health Association
P.O. Box 708
Kent, OH 44240-0708
(216) 678-1601

2. **Differentiate Legitimate Medicine Use From Illegal Drug Use In Drug Abuse Awareness And Prevention Efforts.**
3. **Present Special Programs On Children And Medicine Use.**
 - Include assemblies, PTA meetings, and in-staff training sessions.
 - Involve health professionals in the community in presenting information.
4. **Develop Guidelines For Teachers And School Nurses On Working With Parents And Physicians.**
 - Include the need to monitor medication effects, child concerns, and related classroom behavior. This is especially important with behavioral drugs, such as stimulant medication for attention deficit disorders and medicines for developmental problems.
5. **Develop Policies Regarding In-school Medicine-taking That Facilitate Compliance.**

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