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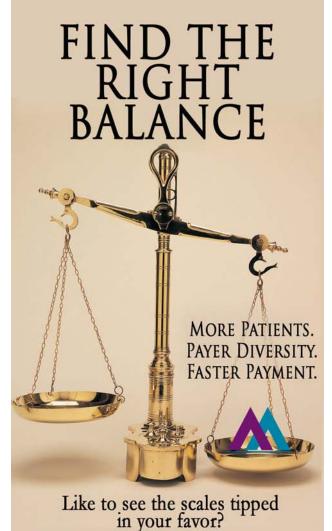
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The Tyranny of the Diagnosis Code

Vergil N. Slee, MD, Debora Slee, JD, and H. Joachim Schmidt, JD

Abstract

The electronic medical record (EMR), while having acknowledged advantages over the paper record and powerful constituencies advocating its adoption, is not in widespread use. One significant obstacle to its acceptance by physicians has not been addressed—its failure to provide easy input for the patient's exact diagnoses and for the retrieval of those diagnoses during subsequent patient care. Furthermore, our system designers have failed to respond to the expansion of the use of the medical record from its origin as simply the physician's memory and communication tool to becoming the building block for our Medical Record Health Information System (MRHIS), where it also supplies the justification for payment for care and is the source of fundamental statistics about health and healthcare. These problems reflect a basic flaw in the application of available information technology to EMR design and data management: We use **output** codes—the category codes from ICD-9-CM—for **input** of diagnoses. This fact imposes the tynamy. Our medical records must have these ICD-9-CM codes for the reimbursement system. But, to be accepted as the basic record for medical care, and at the same time, to be truly useful for case retrieval and statistics, medical informatics experts recognize that our EMR must have codes for the exact diagnoses of the patient (diagnosis entities). But no practical method for their input and management has been offered. This paper proposes a way to provide easy input of diagnosis entities, and their permanent coding, as a workable solution to the problem.

he senior author first encountered diagnosis coding as an intern in the 1940's, when he was told to code the diagnoses in his medical records using "The Blue Book" [the American Medical Association (AMA) *Standard Nomenclature of Disease and Standard Nomenclature of Operations (SNDO)*].

Coding was not [considered] a proper task for "finished" physicians; it was scutwork for the lowest-ranking house officers and a normal duty of experts in the medical record department. The "game" was to use only codes found in the blue book, else I would hear from the medical record librarian.

The Blue Book did not offer any nomenclature I recognized. I had written "diabetes mellitus" in the chart, and that had passed muster with the attending. The closest thing I could find in the book was on page 457: "diabetes mellitus without known cause or structural change." It had a code number, 871-x10, which translated back as "disease of the pancreas, insular tissue," the 871 part, and "depression of function," the -x10 part. I didn't know anybody who used that language, yet the book was, presumably, the standard nomenclature of medicine.

I was at the mercy of the code book. Healthcare information revolved around the code, not the diagnosis itself.²

The reason that diagnoses are coded is that codes are both compact and specific. In those early days, codes were used primarily to organize the hospital's diagnosis index, to which the medical record librarian looked when called on to retrieve medical records-individual "teaching cases" for presentations and series of cases for documenting physicians' experience and for compiling certain professional statistics. There was an index card for each SNDO diagnosis code, and on it were listed the charts where that diagnosis was found. Teaching cases typically were flagged on the index card by written notations. It turned out that, because of the coding to SNDO, to get all the diabetes mellitus cases, for example, one had to look at dozens of cards. Some of them had numbers that were in the Blue Book, but many did not, because they had literally been created "on-the-fly" by the coder, who synthesized a code by taking one piece designating the topography of the diagnosis (the three digits to the left of a hyphen) plus a code for its etiology (the three digits to the right of the hyphen). There was no systematic recording of these ad hoc codes, and many cases were lost because a subsequent searcher did not think the same way as the coder.

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International Classification of Diseases

Help for the retrieval dilemma arrived in the United States in the mid-1950s when a pair of clever medical record librarians³ discovered that the authors of *SNDO*, 4th Edition, 1952, had provided an appendix linking *SNDO* with the *International Statistical Classification of Diseases, 6th Revision* (*ISC-6*) (1948). The appendix listed the most frequent SNDO codes that should be placed in each *ISC* category. The whole purpose of the *International Classifications*⁴ is to group cases for the output, rather than the input, of diagnostic information. And since gathering a series of cases for review or analysis is an "output" function, *ISC* was a godsend.⁵ Thirty of the most common SNDO codings for diabetes, for example, were already listed under ISC-6 Code 260, "diabetes mellitus" in this appendix to *SNDO*.

The immediate question was "Why not cut out the middle man? Let's just use the code we'll want to look up—the *ISC* code—in the first place." That made lots of sense. A study, "Efficiency in Hospital Indexing of the Coding Systems of the ISC and SNDO," published in the *Journal of the American Association of Medical Record Librarians* in 1959 gave a resounding preference to ISC for this purpose, upon which the United States Public Health Service immediately published ISC's first clinical modification, with the impressive title *International Classification of Diseases, Adapted, for Indexing Hospital Records by Diseases and Operations* (short title "PHS 719," 1962).

This was the unnoticed origin of today's tyranny. We began to use, for data input, codes that were never intended for that purpose. They were *output* codes, category codes, designed for grouping diagnoses for statistical purposes.

Clinicians, from the very first, wanted "greater detail." Their ideal was to find individual diagnoses. If this demand had to be satisfied by a single coding system, which appeared the only option, the only answer was "more codes"-subdivide the categories. And over the years, we have gone in that direction. We have far more codes today with the coding system we use, ICD-9-CM,⁶ than were in PHS-719—about 13,000 compared to 2,600. Naturally, most of these categories contain fewer diagnoses than did those of PHS-719, but more than 100 categories still have more than 100 diagnoses each. Now the United States Department of Health and Human Services (DHHS) has produced a clinical modification of the latest Revision of ICD, ICD-10,7 which was finished by World Health Organization (WHO) in 1989 and published in 1992. Its United States clinical modification, ICD-10-CM, which has not yet been published, has grown in draft to 67,000 categories.⁸

Recall that *ICD* was a welcome and proper solution to hospitals' needs when it was adopted. Medical records had to be indexed so that the hospital's information professionals could gather series of cases for local clinical and management purposes, could compile statistics on the hospital's operation, and find individual records that had been specially tagged. For all these uses, codes were the point of access.

But the codes were also employed as documentation in billing third parties for care rendered to individual patients. The codes began controlling reimbursement. And today, many say that reimbursement controls the codes.

Medical Record Health Information System

An additional use of coded diagnosis information appeared in the early 1950s, when hospitals began to compare notes on their professional practices by submitting the local coded data to a central point.⁹

Once started, these external uses of the coded hospital data proliferated rapidly. Investigators studied healthcare. Epidemiologists studied health trends. Public policy increasingly was based on hospital statistics. Today "ICD-CM" coded diagnosis data from physicians' office practice—as reflected in their billing—is an additional source of data for these purposes. This information system, which has evolved over the past decades, is now called the "Medical Record Health Information System (MRHIS)."¹⁰

But these codes—the only diagnosis codes we use—are *category* codes, which means they represent pre-aggregated data.¹¹ As the basic building blocks of our information, category codes have certain inevitable effects. Among them:

- They permit compiling statistics in the schema of only one classification, yet common sense tells us that statistics on hospital usage, for example, should be displayed in different categories than those required for broad public policy. But once aggregated, data can never be disaggregated, it can only be placed in larger groups.
- The complexity of the conventions and rules for category coding results in a very complicated process, distributed among tens of thousands of coders, which greatly increases the risk of inaccurate data—different codes for the same thing. In fact, the error rates for our coding today are an embarrassment.
- When "de-coded," the *ICD-9-CM* codes reveal only the titles of the diagnostic categories, not the unique diagnoses that received the category codes. The diagnoses of individual cases are simply discarded—lost forever.¹² The only way to retrieve specific diagnoses is to review the original medical records, a tremendous task even in a single practice or hospital.

New Opportunities—New Problems

Now we are entering the age of the electronic medical record (EMR)—with all its promise for improved patient care, patient safety, and efficiency—and a new problem arises.

EMR developers understandably make it as easy as possible to get information into the record. For the input of diagnoses they provide a "check-off" list for the physician, who naturally believes that when a diagnosis has been checked, and thus, properly coded, retrieving its code will give back the diagnosis. Usually this is not true.

■ First, there is a *visible* problem. No prefabricated list can contain all possible diagnoses, so the physician must often

settle for "the nearest thing." To handle such problems, the vendor lets the physician add any diagnoses he or she wants to the list. She could just add "avian flu." Such changing of the list is a nuisance, but it seems to solve the problem, at least for the time being and for this individual physician.

Second, there is an *invisible* problem. "Under the hood," the computer takes over and does the coding, coding that is governed by the necessity for providing proper input for the billing system. Billing needs the ICD-9-CM code—the category code that is the basic input for a DRG—so "avian flu" is given its ICD-9-CM category code. When that code is retrieved, what comes back is the label of a category. Thus, "avian flu" may appear to go in, but "influenza with other manifestations" comes out. The diagnosis itself has simply been discarded. This is because an *output* code has been used for *input*. We are using obsolete information processing methods.

This behavior of the record system not only defeats the purpose of recording the diagnosis in the first place, but, when the physician discovers that the diagnosis has actually been changed by the computer, this intrusion becomes a further impediment to the acceptance of the EMR.

For the one episode, this may not be serious, but when the record must serve as the physician's memory in a future encounter and for essential communication among caregivers, knowing only the category title rather than the precise disease may well lead to inappropriate management.

Interestingly, although these facts are recognized and bewailed, rarely are they identified as the problems that should and can be solved. We simply suffer in silence.

We are told that relief is in the offing—our government is considering the replacement of ICD-9-CM. But it turns out that the plans simply are to replace it with a later model of the same obsolete system. Newer category coding will replace the older. The International Classification of Diseases, 10th Revision, Clinical Modification (ICD-10-CM), which has been prepared to replace ICD-9-CM, is the clinical modification of ICD-10. ICD-10 represents international agreement (and international compromises) on how diagnoses should have been grouped (statistically classified) as of 1989, the year of its completion (and ICD-10-CM must conform to its parent). ICD-10 updates the 1975 thinking that produced ICD-9 and, of course, recognizes the new diagnoses that appeared between 1975 and 1989. However, the enormous medical progress since 1989-perhaps greatest in the field of genetics-has no place to go in ICD-10 except in "waste-basket" categories with labels, such as "other chromosomal abnormalities." Such escape hatches are provided in every classification so that every item in its "universe" will have a home.¹³

AIDS is a good example of what happens when a new disease or diagnosis appears. After AIDS appeared in 1981, instructions were given in the United States that in using *ICD-9-CM*, the coder should place AIDS among "other diseases of the immune system." When we later recognized that AIDS is the result of an infection rather than a disorder of the immune system, our national response in 1986 was to instruct coders to use some new codes we gave them among the infectious diseases. But these solutions were local to the United States. Changing AIDS thinking could only be handled internationally (i.e., in *ICD*) by changes in the next numbered revision; WHO has no mechanism for interim classification steps. Not until 1989 did WHO's *ICD* recognize AIDS—with a new category in *ICD-10*. Today, new diagnoses suffer the same fate.

Gulf War Syndrome still has no code. The instructions are "code to 'late effects of war' plus 'the relevant symptom.""

When SARS (severe acute respiratory syndrome) appeared, no coding decision was available as to where to put it until midsummer, effective in October 2003. Even then it only directed the coder to a category. It did not prescribe a unique, unalterable code for SARS.

The bottom line is that the *International Classification*, along with its clinical modifications (and the consequent category coding) will always be lagging behind the real world.

We Need to Know Exact Diagnoses

As noted, to a large extent the clinical modifications in the United States were the result of clinicians' demands for greater specificity, which naturally required more codes. So the first reaction to the information that *ICD-10-CM*, which in its latest draft (dated June 2003) has 67,000 codes¹⁴ while *ICD-9-CM* has only 13,000, is that these must represent smaller categories, and thus give us the greater detail we are seeking. Not necessarily.

In the case of *ICD-10-CM*, the great bulk of the new codes represent "combination categories," meaning that they contain more than one diagnosis or more than one kind of information. Such categories have plagued our information system ever since we got on the *ICD* path. "Myocardial infarction with hypertension" was one code, while there were also separate codes for "myocardial infarction" and "hypertension." In this example, to find myocardial infarction, one must look up two codes, the single code and the combined code. The same goes for hypertension, of course.

One example of "other kinds of information," as well as more than one clinical diagnosis, is taken from the current *ICD-10-CM* draft (June 2003). Code S82 is "Fracture of lower leg including ankle." The category itself has 203 subdivisions, which, for example, separate closed from open fractures for specific bones and bone segments. In addition, the rules require that each code be modified by one of 16 "extension" codes (giving such added information as "initial encounter for closed fracture" ... "subsequent encounter..." "sequela."), so that Code S82 "explodes" into a total of 3,248 codes, each of which contributes to the total count of 67,000.

Where We Are Today

ICD-10-CM is only a vehicle for the output of information which, while useful, was not designed to meet the data input needs of a modern information system. Our system should give us features we simply don't have today. It should:

- Capture and preserve diagnosis detail.
- Permit statistics appropriate to their purposes.
- Avoid the periodic coding upheavals (and enormous costs) inevitable when category coding is used for diagnosis input.

Although DHHS has prepared ICD-10-CM, it has not been published, and the decision to mandate its use has not yet been made. The move should not be made without careful study.¹⁵ The switch from ICD-9-CM to ICD-10-CM would place a huge cost on the health information system, beginning with increased coding costs and those of operating, for a considerable time, a dual coding stream for management of billing for both hospitals and physicians. In addition, such a coding change has literally hundreds of other points of impact in the reimbursement system, including, for example, contracts with physicians. There also would be extensive changes in computer systems and programming-changes which would have to be made and tested before the cut-over. Successful implementation would also require the rebuilding of payment categories, such as DRGs, using both medical and financial data, in order to retain financial equilibrium. The healthcare system could not afford to let either payers or providers suffer.

Even greater, though less tangible, costs could be the result of information loss (largely the interference with longitudinal studies). Information loss, though often not placed under the heading of "cost," is not a trivial matter and may, in the long run, actually cost society more dollars than those required for system changes.

The longitudinal study problem deserves special attention. It stems from the fact that each succeeding generation of the classification necessarily changes the diagnosis categories and their contents. Statisticians are aware of this problem—often studies crossing the date of a coding change must simply be abandoned. In anticipation of the United States switch from *ICD-9* to *ICD-10* for its mortality statistics effective with 1999 data, an estimate of the effect was prepared, using a process called "bridge coding." This was done to minimize, by the use of statistical corrections, the distortion introduced by changes in category content.

Yet, Florida's 1999 AIDS death rate, the first computed using *ICD-10*, unexpectedly rose 6.7%. Recompiling the 1999 data as though the 1998 procedure were still in place (i.e., going back to *ICD-9*) showed a decrease of 6.6%, thus confirming that the "*ICD-10* statistics" were quite contrary to the facts in describing the actual mortality trends.¹⁶ This experience is a serious warning that all mortality trends crossing January 1, 1999 in United States data must be suspect. In fact, mortality data from all nations now using *ICD-10* must be carefully scrutinized in any trends and international comparisons that cross the date of any country's switch. Not all countries switched to *ICD-10* on the same date.

Switching to *ICD-10-CM* would not give us the information system we need and would introduce new problems and costs. A change in procedure coding in hospitals is also under consideration.¹⁷

The System We Should Demand—and Create

In view of today's varied uses for coded information, and with today's information management technology beyond even the dreams of the 1950s, we should demand a coding system that meets one simple requirement:

A proper diagnosis coding system must preserve forever, in coded form, the most detailed diagnostic information in the original medical record, rather than simply the pigeonhole of a classification in vogue at the time of coding. Such "entity" codes can always be decoded to the exact diagnosis terms used rather than retrieving the labels of a classification.¹⁸

There are several advantages.

- The medical record can fulfill its primary purpose as the physician's memory and communication tool. This would be an important stimulus to the EMR's adoption.
- We will be freed from dependence on statistics compiled with a "one-size-fits-all" classification. We can place the diagnoses into as many classifications as desired, each appropriate for its own purpose. Public policy, reimbursement, healthcare administration, epidemiology, clinical research, and evidence-based medicine, each needs its own "tailored" classification.
- Input coding will not have to change whenever classifications are changed, as inevitably they are, to accommodate new views as to classification needs and new knowledge.
- The information professional will be freed to deal with information rather than coding intricacies.

A Proposed Course of Action

If we provide a way to capture and unalterably code the exact diagnoses—the diagnosis entities—in the medical record, all of the features of a proper medical record information system could be achieved.

SNDO was on the right track in that it tried to give us exact, specific terms along with codes for our diagnosis entities. Unfortunately, its method, known as modular coding, gave us terms that were never useful in speaking or writing. Modular coding also failed to cope with the synonym problems and to prevent the synthesis of untraceable codes. In addition, *SNDO* was one example of the impossibility of forcing physicians, or anyone, to use someone else's way of saying things.¹⁹

Diagnosis entities, the exact terms, are already in the medical record as words or phrases. In fact, it is through the use of these terms that a human places the diagnoses in their categories today. So each time a medical record is coded, the coder first locates the precise diagnoses. If each diagnosis were, at that moment, given a permanent, unalterable code, we'd have what we need.

Granted, this would mean adding another coding system, "ahead" of (actually parallel with) our present coding to *ICD-9-CM*, which we need for reimbursement, but this addition should not be difficult. Our present technology is fully up to the task.

Medical informaticians agree that the medical record should carry the diagnosis entities, and the exact diagnoses should be expressed using a standard vocabulary so all medical records containing the same diagnosis couch it in the same "preferred" or standard term. But implementing this idea has been slow because of the assumption that the input of each diagnosis would be done by either entering the standard term directly or checking it off from a list of standard terms.

This assumption implies that, to accomplish this, we must (1) provide, at the point of care or coding, a complete standard vocabulary (i.e., one containing every term a physician might want to use) and then, (2) enforce its use.

Both portions of this proposal are fatuous. We can never have a complete standard vocabulary (it will always evolve), nor can we envision a world in which everyone can be forced to speak "correctly" (i.e., like an authority says they should) consider dialects, ethnic backgrounds, education, geographic region, and similar confounding influences. Yet, one must agree with the desirability of having the diagnoses in the records expressed in the same terms. The problem lies with attempting to require that the *input* be in the standard or controlled terms.

We propose that the input of diagnoses should be in *free vocabulary*, letting the physician use whatever terms he or she wants to use, and then have the computer map these synonyms into a *standard vocabulary*.²⁰ This would solve the problem, and developing the necessary system appears to be a manageable task.

We would need to start the system by establishing a master database containing as many as possible of the terms already in the diagnosis universe, both those expressed in free vocabulary form and those in standard vocabulary form, i.e., "preferred terms" (those diagnoses not in standard vocabulary are, by definition, synonyms for those that are in standard form). This database would be managed by a single, central clearinghouse, the "*Secretariat*."

The great majority of diagnostic terms that would be encountered are already in use, and a list of them could readily be created by gathering together diagnostic terms from such sources as the index to *ICD-9-CM* and the indexes to medical journals and texts. Each one identified as the "preferred" or standard term would be so tagged, and all its synonyms would be mapped to its corresponding standard term.²¹

A term not found in the master database would represent one of two things:

- A new synonym for an existing diagnosis. The Secretariat would identify it as such and map it to its "parent" standard term. Or it would be
- A new diagnostic entity. The Secretariat would record it in the database. and it would be tagged to identify it as a term that had not previously been encountered. The system would later be able to handle this ambiguity by replacing the provisional tag with its unique permanent tag when the new diagnosis had been properly studied and a preferred term assigned.

Each diagnosis term, whether in free or standard vocabulary form, would be assigned its own unique, permanent, unalterable code, called an "*entity code*." Each code would always carry (and would be tagged with) information as to its origin, so that its meaning would be unequivocal. A serious flaw in our current coding system is that there is no way to be sure of the code system to which a given code belongs. Thus, it cannot be unambiguously interpreted.

The master database would contain all free and standard vocabulary diagnosis entities along with their entity codes. This could be called the "*Diagnosis Entity Code Database*."

Today's "central" vocabulary systems are not designed to operate in "real-time," which would be required if the proposed system were to be practical for use in input for the electronic medical record, so a significant system design challenge is posed. The Secretariat could be organized so that a permanent code could be assigned and furnished to the coder at once for every term encountered, perhaps via the Internet, so that the code could be included immediately in the medical record. This would preserve the diagnosis in the medical record not only with the exact free vocabulary term, but also its unique code.

The system should also be designed so that when a *new* diagnosis has been properly studied, the original medical record can be edited and the term tagged as either a new preferred term or as a synonym for a new preferred term, which is simultaneously supplied.

The system, once implemented, would work as follows. First the medical record would accept the diagnoses in natural language (i.e., in free vocabulary), which may often be the standard term exactly, but the physician will not be *required* to find and use some prescribed term. The input method could be similar to that of the financial program Quicken[®], which finds the "payee" name as one types in the string of characters, jumping quickly ahead as it matches what is already there. When the desired entity term is found, it would instantly be given its entity code. Even if it is a new term, a code (essentially an accession number) would be supplied immediately by the system. This is possible because there is no need, at this point, to classify the term nor to map it to its standard form.

If the term is a synonym for a standard diagnostic term, that term and its entity code would also be supplied immediately by the system and recorded in the medical record. Thus, all medical records would contain the same diagnostic language, but the system would not impede or bias the input, which would be the case if the physician had to choose an approved term in order to record the diagnosis initially.

This proposed system would not in any way interfere with our current coding to *ICD-9-CM* nor impede switching to *ICD-10-CM*. In fact, continuing our present coding to *ICD-9-CM* would avoid interruption of the reimbursement process. In future, it would be a simple matter to use the diagnosis entity codes to map cases into *ICD-10-CM*, for example, or into any classification created for standard or ad hoc purposes. This might include a new billing code or a unique classification for specific research. No input coding change would be required ever again—computer programming would take care of the task of classification. Thus, if *ICD-10-CM* should be adopted in the clinical world, the disruption to our current coding system would be minimal, compared to the enormous upheaval we are facing today.

The illustration below shows the proposed coding system compared with the present system.

The proposed system would require the following elements:

- *Secretariat.* An organization to centralize the establishment and maintenance of the system as a national resource.
- Standard Diagnosis Vocabulary. An agreed-upon standard, "controlled," vocabulary, perhaps to be called the United States Standard Diagnosis Vocabulary. Such a vocabulary may prove to be that provided by SNOMED CT²²
- Diagnosis Entity Code Database. This would preserve all terms encountered—both free vocabulary and standard vocabulary—and their entity codes, along with supporting information for each. All synonyms would be mapped to their standard, "preferred" terms. In the case of new terms, Secretariat staff could study their meanings and provide the mapping decisions within, perhaps, 48 hours. New diagnoses could be recorded and tracked immediately.

Current vs. Proposed Diagnosis Coding

ICD-9-CM

CODE

CURRENT

DIAGNOSIS

Code To

DISCARDS

EXACT

DIAGNOSIS

Figure 1.

- Classification Rules. Mapping of the standard vocabulary codes into various classifications. Mapping to ICD-9-CM, for example, could be a function of the existing clearinghouse for ICD-9-CM.
- Communication. Interrogation of the entity code database would have to be immediate, via Internet and other means, to provide the entity codes and mapping in a timely fashion, so the processing of medical records would not be delayed.

Conclusion

PROPOSED

DIAGNOSIS

Code To

ICD-9-CM

CODE

FREE DIAGNOSIS

VOCABULARY

CODE

Map To

STANDARD DIAGNOSIS

VOCABULARY CODE SNOMED CT ??

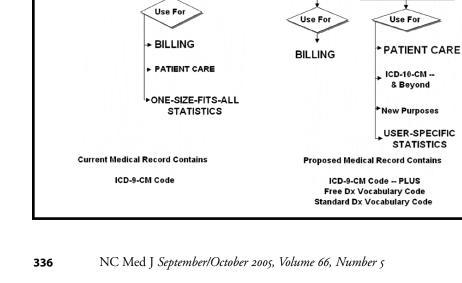
Our health information system is irretrievably codedependent. What makes our codes tyrannical is that we don't have codes that carry the right information. In the case of diagnoses, we need "payment" diagnosis codes for our reimbursement system, and these we already have in *ICD-9-CM*. For all other uses, we need diagnosis entity codes. With entity codes, we can break the tyranny and free our information system to serve us rather than control us.

It is puzzling that at the beginning of the 21st century our management of diagnostic information does not give us the specificity and flexibility we need. The great bulk of the other information in the medical record is already in detailed, accessible form. Age is detailed to the minute for newborns;

administration detail is exact to the drug, dosage, and schedule; and patients' physical characteristics are recorded in detail, as is their demographic information.

Today's computer technology also makes it easy to handle great masses of detail, which can supplement or clarify diagnostic statements. For example, it could be clear whether the diagnosis of diabetes was made when the blood sugar level required was 120 or after the standard was lowered to 110 (that simple definition change reportedly added about 2,000,000 diabetics to the national load with the stroke of a pen). A diagnosis of HIV infection would be much more meaningful if the T-4 count were attached. AIDS would be clarified if the opportunistic infections that were considered in making the diagnosis were also visible. The credibility of a SARS diagnosis could be checked by looking for supporting laboratory results. All these possibilities are within our technology. All we lack is the "substrate" that diagnoses in entity form would complete.

Breaking the tyranny of today's diagnosis category codes is a straight-forward task that should be given high priority. **NCMedJ**



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- 2 Siee VN. The Silent Threat to Our Personal [and National] Health, Partnerships, Vol. 17, Fall 2003, Health Commons Institute.
- 3 Kurtz D. CRL of Columbia-Presbyterian Hospital in New York and Loyola Voelker, CRL, of the USPHS Hospital in Baltimore.
- 4 The International Classification series is published every 10 to 15 years by the World Health Organization (WHO). Formerly named the International Statistical Classification (ISC), it was renamed the International Classification of Diseases (ICD) with the 7th Revision, in 1955.
- 5 A few "clinical modifications" were necessary to meet the needs of U.S. hospitals. "Clinical modification" primarily means subdividing categories in order to provide greater detail. For example, Code 260, Diabetes mellitus, was immediately given, in the United States modification, seven subdivisions. Of course, these were collapsible into code 260 in order to create the original broader group.
- 6 International Classification of Diseases, 9th Revision, Clinical Modification (ICD-9-CM). Since the International Statistical Classification was renamed to International Classification of Diseases, it has been commonly referred to as "ICD," regardless of its actual long title, which continues to evolve. All "clinical" coding, i.e., hospital and office coding, uses the clinical modification (CM), not ICD as published by WHO.
- 7 International Statistical Classification of Diseases and Related Health Problems, Tenth Revision, WHO, 1992.
- 8 ICD-10-CM is a product of the United States National Center for Health Statistics. The first draft was displayed on the Internet in 1997; the latest draft on the Internet is dated June 2003. But since it is still a draft, it presents a moving target, and the numbers of categories, for example, may be far different in a final product. Its basic structure, however, is mandated by conformity to its WHO "parent," ICD-10.
- 9 The Professional Activity Study (PAS), the first "hospital discharge abstract system," was established in the Southwestern Michigan Hospital Council in1954 by the senior author under a grant from the W. K. Kellogg Foundation in order to compare statistics on medical care and experience among its hospitals. See Slee VN, Slee DA, Schmidt HJ, The Endangered Medical Record: Ensuring Its Integrity in the Age of Informatics, Tringa Press, 2000.
- 10 Slee, et al. The Medical Record Health Information System (MRHIS). Available at www.tringa.come.
- 11 Category coding is coding in which each code (number) represents the label (rubric) of a category rather than an individual term being coded. Category coding is designed to achieve grouping to established classification "pigconholes" in a single step which combines coding and classifying. From Slee VN, et al. "Slee's Health Care Terms," 4th Edition 2001.
- 12 There are, of course, single-diagnosis categories in ICD-9-CM. But another patient with that diagnosis may have been placed in another category because, for example, the diagnosis may also be in a combination category. Diagnosis retrieval is not a simple task.
- 13 It is possible, through a United States committee process, to make changes in the clinical modifications, usually on an

annual basis, effective each October. Thus a subdivision to an ICD-10-CM code could be made, for example, for avian flu if the committee so chose. Then its use would be turned over to the thousands of coders in hospitals and physicians' offices. In any case, the provision for avian flu would be late, and would apply only to United States users; it would never influence the international mortality statistics, which would still be tied to the 1989 categories in ICD-10 (WHO).

- 14 Slee VN, DA Slee, and HJ Schmidt, ICD-10-CM: A Close Look, August 2004. Available at www.tringa.com.
- 15 On April 13, 2004, Draft Recommendations from the Health Care Delivery and Information Technology (HIT) Subcommittee of the President's Information Technology Advisory Committee (PITAC) stated: "A specific study should reassess the cost-benefit of the planned conversion of diagnosis and procedure coding requirements for Federal programs from...ICD-9-CM to ICD-10-CM, compared to the potential alternative of moving directly to...SNOMED CT [Systematized Nomenclature of Medicine (SNOMED) Clinical Terms (CT), published by the College of American Pathologists.]. This might provide incentives for standardized EHR [Electronic Health Record] implementations."
- 16 Grigg, et al. Research Letter: Coding Changes and Apparent HIV/AIDS Mortality Trends in Florida, 1999. JAMA 2001; 286(15):1839.
- 17 The switch would also require a decision as to the coding to employ for procedures in hospitals-whether or not to retain ICD-9-CM's third volume, which contains the procedure code system now in use. ICD-10-CM does not have a procedure code, so DHHS commissioned the creation of ICD-10 Procedure Coding System (ICD-10-PCS). ICD-10-PCS, using a modular structure, offers an exquisitely detailed way to code millions of individual procedures-although not a method for capturing the physician or surgeon's usual language. In its specificity it achieves the goal of being truly designed for the input of data. However, for billing and statistical purposes, its codes likely will have to be collected into categories yet to be specified. For example, an "operation" often consists of an aggregation of several procedures which are individually codable in ICD-10-PCS. And the decisions to adopt ICD-10-CM and/or ICD-10-PCS are independent-one could be adopted without the other, and vice versa.
- 18 Entity coding is coding in which each code represents an individual entity (term) rather than a category (group) of terms. In entity coding, each entity (specific term) to be coded (for example, a diagnosis or procedure) is exchanged for a code (number) which, when decoded, yields exactly the same words (term) which were coded. From Slee VN, et al. "Slee's Health Care Terms," 4th Edition 2001.
- 19 A later attempt at a forced vocabulary, also by AMA, was its series of Current Medical Terminology (CMT) publications, begun in 1962 and abandoned in 1971.
- 20 This proposal imitates the wisdom as to how to know where to place the paved walks on a campus—pave the paths that people make.
- 21 Systematized Nomenclature of Medicine (SNOMED) Clinical Terms (CT) uses this convention—codes are unique, unalterable, nonreusable, and are "tagged" to indicate whether they are the preferred term for a given diagnosis or a synonym, and if synonyms, their "parent" terms are given.
- 22 Systematized Nomenclature of Medicine (SNOMED) Clinical Terms (CT), published by the College of American Pathologists.

Call for Papers

John W. Williams, Jr., MD, MHS Scientific Editor, North Carolina Medical Journal

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Medical Journal

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Medical Journal

Comments and a Response to "The Tyranny of the Diagnosis Code" by Slee and Colleagues

David C. Kibbe, MD, MBA

I'd like to heartily applaud the article, "Tyranny of the Diagnosis Code," by Virgil Slee, Debora Slee, and HJ Schmidt, which offers us a wealth of insight and historical perspective on medical coding. I welcome this thoughtful essay especially because it comes to us just as the United States healthcare system is embarking on what I call the Era of Medical Measurement, and the authors remind us of just how much is at stake for physicians and medical practices in the choices that are made about information management and components of health information technology systems.

Let me digress slightly. The American Academy of Family Physicians (AAFP) has publicly gone on record as being supportive of plans to improve the quality of healthcare through the collection, storage, analysis, and reporting of clinical quality and efficiency measures. In a recent letter to leaders of Congress, for example, we stated: "We believe that the medical profession has a professional and ethical responsibility to engage in activities to continuously improve the quality of care provided to patients. The Institute of Medicine's landmark report, Crossing the Quality Chasm, documented significant gaps in healthcare quality and issued a challenge to the profession to work collaboratively to improve quality, safety and access. Our organizations accept this challenge...^{"1} The AAFP was joined in this letter by the three other major primary care specialty organizations, the American Academy of Pediatrics (AAP), the American College of Physicians (ACP), and the American College of Obstetricians and Gynecologists (ACOG). Together, these physician membership organizations represent over 250,000 doctors in practice in the United States, and their members' work accounts for over 60% of all ambulatory care and outpatient visits in the United States each year.

This unanimity of opinion from the primary care medical specialty societies on the issue of quality is but one of many indications and signals that lead me to believe we are fast approaching a national consensus that the time has come to implement a uniform, all-payer quality and performance measurement program for the multiple purposes of achieving quality improvements, supporting value-based purchasing (also known as pay-for-performance), and enhancing public accountability. While not wishing to minimize the large-scale nature and complexity of such a program, I have observed growing optimism from the public, federal and state governments, physicians and their organizations, private sector health plans, the business community, and many others about the potential to accomplish this aim in the near term. There appears to be a new willingness of the parties to engage collaboratively in a new frontier for healthcare in which measurement of performance plays a central role and also a new confidence in the capability of the standards, methods, and technologies now available, or nearly within our grasp, which are so necessary to the accomplishment of such a complex effort.

One powerful example of this trend is the recent consensus reached by the Ambulatory Care Quality Alliance (AQA) on standardizing ambulatory care quality and performance measures. The AQA is a multi-stakeholder group representing physicians, health plans, employers, the Centers for Medicare and Medicaid Services (CMS), patient advocacy organizations, and many others. The AAFP was one of AQA's initial conveners, along with the American College of Physicians (ACP), America's Health Insurance Plans (AHIP), and the Agency for Healthcare Research and Quality (AHRQ). In June of 2005, within six months of being formed, the AQA reached consensus on a national "starter set" of 26 evidence-based clinical performance measures for the ambulatory care setting. The starter set of 26 measures is intended to provide clinicians, consumers, and purchasers with a single set of quality indicators that may be utilized for quality improvement, public reporting, and pay-for-performance programs. It is comprised of prevention measures for cancer screening and vaccinations; measures for chronic conditions, including coronary artery disease, heart failure, diabetes, asthma, depression, and prenatal care; and two efficiency measures that address overuse and misuse.

Uniformity with respect to the performance measures employed by Medicare, Medicaid, and the many private health insurance plans across the country is an essential foundation for making meaningful comparisons of physician performance across geographical regions and across different payer groups in any area and a prerequisite for standardized use of physician-

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level data for value-based purchasing programs (also known as pay-for-performance) by Medicare. Having a single set of measures that can be reported by a practice to different health plans with which the practice is contracted is also critical to reducing the cost burden of reporting measures borne by individual medical practices. Therefore, the consensus agreement reached by AQA in June, 2005 was a genuine milestone in the progress toward a national quality and performance measurement program.

There are clear signs from CMS that a federal mandate for submission of quality and efficiency measures from medical practices, tied to differential reimbursements for care of Medicare beneficiaries, will be initiated as early as 2006. A spate of recent and mostly bi-partisan health information technology legislation, such as the "Wired for Health Care Quality Act," co-sponsored by Senators Frist, Kennedy, Enzi, and Clinton, contain provisions that require medical practices to routinely submit quality and efficiency data as a consequence of receiving federal funding through grants or loans associated with local, state, or regional health information technology initiatives. Meanwhile, dozens of pay-for-performance programs have sprung up in the private sector, sponsored by individual and private health plans, insurance companies, and corporate payers of employee healthcare bills. The largest and most often cited of these are the Integrated Healthcare Association's (IHA) pay-for-performance program in California—the largest of its kind to date involving seven major health plans, over 215 medical groups, and over six million HMO enrollees-and the Bridges to Excellence program,² which has clearly demonstrated that EHRs in small and medium size medical practices can be effectively used to collect, analyze, and report quality and performance data. But there are many other similar programs in more than 25 states.

All of this measurement activity at the physician level rests on the foundation of the existing medical vocabularies and coding systems, which the Slee article discusses. If I am correct that we are about to engage in a large-scale national effort to aggregate data from administrative, (e.g., billing and clinical information produced from health insurance claims systems and EHRs), then there is no question that the great majority of these data will be encoded in ICD-9-CM (and I would include mention of CPT-4 and SNOMED), a set of codes that Slee et al. characterize as classification *output codes* derived primarily for the purposes of financial transactions and hospital statistical analysis, rather than being *input codes* describing what doctors and patients actually experience.

Just the thought of building a national system of outcomes measurement, which not only may affect future health policy in this country, but may also determine how much doctors get paid, on such a shaky foundation as ICD-9-CM should give all physicians reason to pause and contemplate where we are headed. I expect that at the present time, there is neither the political nor economic will to reverse course and take up the solution that Slee et al. propose, namely the establishment of a new super coding set and standard vocabulary capable of diagnosis entity and episode identification. We may have yet to experience the untoward and unintended consequences of measuring things falsely or inaccurately in enough programs and projects to be able to see the wisdom in the course that Dr. Slee and his colleagues recommend.

However, I for one do think we'll get there eventually. Britain's pay-for-performance program for general practitioners using the Quality Management and Analysis System is beginning to generate anecdotes that suggest changes in physician and practice behaviors may not be precisely those sought after. For example, it may be that physicians and nurses are now shifting their focus of attention, perhaps only slightly, from caring for the problems patients bring to them, toward fulfilling the tests and other measures determined by the diagnoses already carried by patients, (eg e.g. diabetes, congestive heart failure, etc.).^{1,3} In other words, the measurement system may have the unintended consequence of encouraging more attention to those diagnoses for which measurement is attached, and less to those where there are no measurements. It is the latter activity that earns British physicians significant bonuses through the National Health Systems' Service's new pay-for-performance program. Since the ICD-9-CM and ICD-10-CM coding systems are firmly embedded in this exercise, we may ulitimately learn from the British experience-and from our own-that which Slee et al. warn us about: measuring the wrong information will not make our healthcare system right. NCMedJ

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- 2 Information on the Bridges to Excellence Program is available at: http://www.bridgestoexcellence.org/bte/.
- 3 Personal correspondence with Kevin Peterson, MD, after his recent 2005 visit to England, during which he visited a number of primary care practices.

POLICY FORUM *Preventing Child Abuse and Neglect*

Introduction

Gordon H. DeFriese, PhD, and Kristie Weisner Thompson, MA

Issue Brief: Preventing Child Maltreatment in North Carolina: New Directions for Supporting Families and Children

Michelle Hughes, MA, MSW, Marian F. Earls, MD, FAAP, Carmen Hooker Odom, MRP, Kristen L. Dubay, MPP, Anne R. Sayers, MSW, Jennifer Tolle Whiteside, MA, and Pam Silberman, JD, DrPH

"Preventing child maltreatment will necessitate a shift in policy toward maximizing and normalizing early assistance to parents to support family environments that nurture and protect children from physical and psychological harm."

COMMENTARIES

The Impact of Maltreatment on the Developing Child Dana M. Hagele, MD, MPH

Building an Effective Child Maltreatment Surveillance System in North Carolina Adam J. Zolotor, MD, MPH, Brenda McAdams Motsinger, MS, RD, LDN, Desmond K. Runyan, MD, DrPH, and Catherine (Kay) Sanford, MSPH

Risk and Protection in the Perpetration of Child Abuse *Kenneth A. Dodge, PhD*

Reframing the Issue: A New Child Maltreatment Prevention Message Becky A. Wrisley

The Role of Primary Healthcare Providers in Preventing Child Maltreatment *Marian F. Earls, MD, FAAP*

A New Paradigm for Child Protection: Begin at the Beginning *Wanda M. Hunter, MPH*

Child Abuse Homicides: A Special Problem within North Carolina's Military Families Marcia E. Herman-Giddens, PA, DrPH, and Thomas J. Vitaglione, MPH

Strengthening Families: The Role of Community-Based and Grassroots Organizations Henrietta J. Zalkind, JD, and Pat W. Allen, MS

The Circle of Parents[®] Program: Increasing Social Support for Parents and Caregivers *Katrina D. Gay, BSPH, MPH*

The Role of Philanthropy in Child Maltreatment Prevention Efforts *Rhett N. Mabry*

INTRODUCTION

Policy Forum: *Preventing Child Abuse and Neglect*

"If child maltreatment were a communicable disease, it would long ago have been declared an epidemic!" This is a quote from Tom Vitaglione, Senior Fellow of the North Carolina Child Advocacy Institute, in his letter to the editor of the *Raleigh News & Observer* (Sunday, September 25, 2005). Vitaglione was writing in response to series of articles in the *News & Observer* describing the alarming rate of "shaken baby syndrome." Child abuse and neglect have enormous consequences for the health of infants and children and great cost implications to the state of North Carolina as abused children's problems evolve into medical, social, legal, and other needs.

Despite the enormous social and economic consequences of child maltreatment, most of our attention and state resources focus on investigating cases of abuse and neglect and providing child welfare services, rather than on prevention strategies. For this reason, Prevent Child Abuse North Carolina, a private, nonprofit organization, with support from The Duke Endowment, partnered with the North Carolina Institute of Medicine in a year-long task force effort to create a state-wide plan to prevent child maltreatment.

The Task Force addressing these issues was co-chaired by Carmen Hooker Odom, Secretary of the North Carolina Department of Health and Human Services, and Marian Earls, MD, FAAP, Medical Director of Guilford Child Health, Inc., in Greensboro. Building on evidence that families with adequate support systems are less likely to abuse their children, the Task Force developed strategies and recommendations by which North Carolina could address this enormously complex and heart-wrenching set of problems. These recommendations are summarized in this issue of the *North Carolina Medical Journal*.

We have invited a number of the state's leading authorities on child maltreatment to contribute to this issue of the Journal. They bring the perspectives of state and local government, health professionals, social service agencies, law enforcement and juvenile justice, academic researchers in the field of child development, legislators, and the faith community. Even before the Task Force was convened in September of 2004, there was widespread consensus that "something had to be done" to reduce the incidence of child maltreatment in our state. With over 113,000 children reported to child protective services agencies each year, and at least 27,000 substantiated as cases "in need of services," this issue is one of our most significant health problems. As Vitaglione points out, this means more than 75 children per day are abused by a parent or caretaker. The report of the North Carolina Institute of Medicine Task Force, developed in partnership with Prevent Child Abuse North Carolina, offers a number of sensible, cost-effective proposals for what can be done about this escalating set of problems affecting the health and lives of our children. If we fail to take these recommendations seriously, we have only ourselves to blame for what will surely become an even larger problem with many consequences for the health and well-being of all North Carolinians.

We look forward to the reactions of our readers to these important ideas communicated through the Journal's Policy Forum.

Gordon H. DeFriese, PhD Editor-in-Chief Kristie Weisner Thompson, MA Managing Editor

Preventing Child Maltreatment in North Carolina: New Directions for Supporting Families and Children

Michelle Hughes, MA, MSW, Marian F. Earls, MD, FAAP, Carmen Hooker Odom, MRP, Kristen L. Dubay, MPP, Anne R. Sayers, MSW, Jennifer Tolle Whiteside, MA, and Pam Silberman, JD, DrPH

C hild maltreatment is a significant and preventable public health problem in North Carolina, and across the United States. It affects millions of children and their families each year in our country—often devastating children's psychological and physical well-being, tearing families apart, and costing our society billions of dollars in services to respond to and treat child victims. In North Carolina alone, 113,557 children were assessed for child maltreatment in 2003-2004, and 27,310 were substantiated, or found to be "in need of services."¹ For too many North Carolina children, maltreatment is fatal. In 2003, 30 children were killed by their parents or caretakers in our state as a result of being shaken, beaten, stabbed, poisoned, or drowned.²

As alarming as these numbers are, they are likely the tip of the iceberg, as child maltreatment is significantly underreported and difficult to detect. For example, the CarolinaSAFE survey an anonymous, random telephone survey of mothers of children (0-17 years old) in North and South Carolina—found that mothers self-reported physical abuse of their children (by either themselves or their husband or partner) at a rate more than 40 times higher and sexual abuse at a rate more than 15 times higher than rates found in official statistics.³ Findings from this study and others suggest that the actual incidence of maltreatment may be much higher than official estimates.⁴

Definitions of Child Maltreatment

Child maltreatment is an act, or a failure to act, which results in significant harm or risk of harm to a minor.⁵ It varies in terms of frequency, severity, and duration with some children experiencing maltreatment primarily during stressful periods or periods of transition within their families, and other children experiencing chronic maltreatment throughout their childhood.⁶ Parents, family members, caregivers, or other adults may commit maltreatment, but the vast majority of maltreatment is perpetrated by a parent or parental figure within a family.^{4,7}

Typically, professionals recognize four types of child maltreatment: physical abuse, neglect, sexual abuse, and emotional/ psychological abuse.⁸ In many cases, children experience multiple forms of maltreatment simultaneously (e.g., physical abuse and emotional abuse),⁹ and they may experience multiple forms of violence within their family, such as maltreatment and domestic violence.¹⁰⁻¹²

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The Costs of Child Maltreatment to Families and Communities

The consequences of child maltreatment can be devastating, not only for the children who are its victims, but for their families and the larger community. In children, especially young children, child maltreatment can adversely impact brain development and forever change the ways in which children think, feel, and behave.¹⁶ Child maltreatment is a form of trauma that can lead to altered brain activity and structure among children who experience chronic and recurrent maltreatment.¹⁶

Children's brains develop in response to repetitive stimuli.¹⁶ Daily experiences with caretakers that are nurturing, stimulating, and developmentally appropriate will help the child's brain develop normally and will form a life-long foundation for optimal growth and learning. However, frequent experiences that are frightening, painful, rejecting, or stressful will, over time, adversely change a child's brain structure and function. Chronic maltreatment (including sensory deprivation from neglect) may result in loss of brain volume and brain complexity.^{17,18} Children's response to chronic stressful stimuli will eventually create maladaptive neural systems leading to a host of negative outcomes, including developmental delays, such as speech and motor problems, behavioral and emotional disorders, and cognitive delays.¹⁶

Recent research has also demonstrated a strong correlation between child maltreatment and long-term health problems, such as heart disease, pulmonary disease, obesity, alcoholism, substance abuse, smoking, and depression. The Adverse Childhood Experiences study is a collaborative effort between the Centers for Disease Control and Prevention and Kaiser Permanente's Health Appraisal Clinic in San Diego of 17,000 HMO members, which found that adverse childhood experiences, such as maltreatment, domestic violence, and other forms of family disfunction are major risk factors for the leading causes of illness and death, as well as poor quality of life in the United States.¹⁹ The research found a "dose-response" relationship in which a greater number of adverse childhood experiences was associated with an increased risk for health and mental health issues throughout the lifespan.²⁰

Clearly, child maltreatment is a social problem with far-reaching and devastating consequences for the health and mental health of our children and for the state's population overall. While the personal costs of child maltreatment to children and families are significant, the economic costs of child maltreatment to communities are also quite staggering. Prevent Child Abuse America estimates that the expenditures associated with child maltreatment in the United States amount to \$94 billion annually,²¹ after including costs such child protective services, court proceedings, health and mental health treatment, special education programs, incarceration, and loss of employment. North Carolina's share of these costs approximates \$3 billion each year.²²

Child Maltreatment Definitions^{*}

Child physical abuse includes physical injuries that result from caretaker actions that can include punching, beating, kicking, biting, shaking, throwing, stabbing, choking, hitting with a hand or other object, or burning. Child physical abuse may be a single incident, or it may be repeated episodes. Consequences can range from minor bruises or marks to death.⁸

Child neglect includes a wide variety of caretaker behavior. Neglect is a failure to provide for a child's basic needs: physical, educational, or emotional. Physical neglect can include refusal of or delay in healthcare, abandonment, expulsion; inadequate supervision; inadequate nutrition, clothing, or hygiene; conspicuous inattention to avoidable hazards in the home; and reckless disregard for a child's safety and welfare. Educational neglect can include permitted chronic truancy, failure to enroll a child in school, or inattention to special education needs. Emotional neglect can include inadequate nurturing or affection, exposure to chronic or extreme spousal abuse, or refusal or delay in psychological care.⁸

Child Sexual Abuse is any sexual activity with a child where consent is not or cannot be given.^{13,14} It can involve contact or noncontact activities. Contact child sexual abuse can include fondling of the genital area or breasts; masturbation; or oral, vaginal, or anal penetration by a finger, penis, or other object. Noncontact child sexual abuse can include exhibitionism, child pornography, Internet crimes, or sexually suggestive behaviors or comments.⁸

Child Emotional/Psychological Abuse is defined by the American Professional Society on the Abuse of Children (APSAC) as "a repeated pattern of caregiver behavior or extreme incident(s) that convey to children that they are worthless, flawed, unloved, unwanted, endangered, or only of value in meeting another's needs." The terms emotional and psychological abuse are often used interchangeably. APSAC guidelines refers to six categories of psychological maltreatment that include spurning; terrorizing; isolating; exploiting/ corrupting; denying emotional responsiveness; and mental health, medical, and educational neglect.¹⁵

*These are broad definitions of child maltreatment. Legal definitions vary among states. North Carolina's legal definitions can be found in the North Carolina General Statutes, Chapter 7B at www.ncleg.net.

Negative Outcomes of Child Maltreatment

Children who are maltreated are significantly more likely to experience the following negative outcomes.

- Serious physical injuries, including subdural hemorrhages, burns, or bone fractures²³
- Delayed physical growth ²⁴
- Permanent physical disabilities²⁵
- Long-term health problems, such as ischemic heart disease and chronic obstructive pulmonary disease (COPD)¹⁹
- Neurological damage¹⁶
- Post-traumatic stress disorder²⁵
- Depression, low self-esteem, and problems with self-regulation of emotions^{26,27}
- Suicidal behavior²⁸
- Increased substance abuse and/or alcohol abuse^{29,30}
- Poor school performance^{31,32}
- Aggression and/or behavior problems in school³³
- Criminal activity³³
- Problems with social relationships; developing trust and attachments^{34,35}
- Adolescent pregnancy³⁶

The Need for Prevention

Historically, North Carolina-like the rest of the nationhas focused its attention primarily on responding to the problem of child maltreatment, not on preventing the problem from occurring in the first place. Following the publication of Henry Kempe's article "The Battered Child Syndrome" in the Journal of the American Medical Association in 1962, there was increased public and policy recognition of child maltreatment as a significant social issue.³⁷ The passage of the Child Abuse Prevention and Treatment Act of 1974 lead to federal support of and increased uniformity among state's child protection systems. North Carolina's child protection system is supported by federal and state legislation and funding and garners a considerable degree of public support for its mission. While there are numerous critics of the child protection system who question its capacity to truly protect children from harm, there is no question that there is a system, however flawed some may find it.

Child maltreatment prevention efforts, however, have not been organized into a set of coordinated activities in North Carolina. Instead, local communities have been left to develop services with little federal or state guidance on best practices and few comprehensive policies to direct programmatic efforts or system development. Funding is fragmented across multiple systems, with little shared planning or shared outcomes among agency programs and initiatives. While many communities (with little funding or support) have developed an array of services for families in need, many of the interventions provided are untested, and many have been unable to effectively serve higherrisk families who suffer from multiple stressors, such as substance abuse, domestic violence, or mental illness. Furthermore, because there is no "system" for child maltreatment prevention, services are often not programmatically linked across different public systems and private nonprofit organizations that serve families and children. Enhancing North Carolina's child maltreatment efforts will require addressing these issues and others in order to ensure that families receive high-quality, timely, effective support services to prevent the development of behaviors that jeopardize the health and well-being of their children.

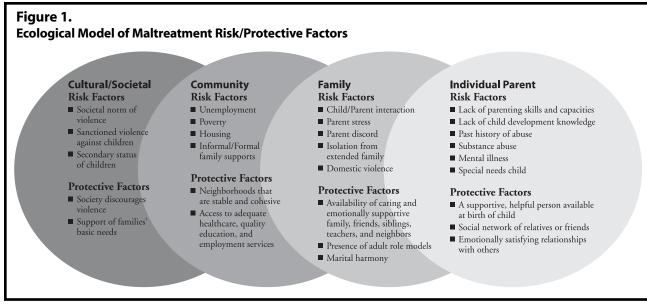
Developing a Statewide Prevention Initiative

To identify strategies that will enhance prevention efforts in North Carolina, the North Carolina Institute of Medicine, in conjunction with Prevent Child Abuse North Carolina (PCA North Carolina), convened a statewide Task Force on Child Abuse Prevention.^a The work of the Task Force was generously supported by The Duke Endowment. Carmen Hooker Odom, Secretary of the North Carolina Department of Health and Human Services, and Marian Earls, MD, FAAP, Medical Director of Guilford Child Health, Inc., co-chaired the Task Force. The 51-member Task Force included state and local representatives of health and human services, education, and juvenile justice agencies, legislators, community-based service organizations, healthcare providers, child advocates, community and business leaders, academicians, researchers, and the faith community. The Task Force met for approximately nine months, September 2004 through June 2005.^b

The goal of the Task Force on Child Abuse Prevention was to develop a statewide plan that focused on preventing maltreatment before it occurs, rather than on responding to and intervening in cases of child maltreatment. To accomplish this, the Task Force had three significant goals: (1) create a common understanding of the risk and protective factors associated with child maltreatment and how prevention strategies might target those factors; (2) forge a vision to guide the development of a child maltreatment prevention system in North Carolina; and (3) develop recommendations to enhance the state's prevention efforts.

a Prevent Child Abuse North Carolina is a statewide nonprofit that conducts professional training, public education, assistance with program development, and advocacy.

b A full copy of the Task Force's report can be found on the North Carolina Institute of Medicine's Web site at: www.nciom.org. North Carolina Institute of Medicine. New Directions for North Carolina: A Report of the North Carolina Institute of Medicine Task Force on Child Abuse Prevention. September 2005. Durham, NC.



Understanding Risk Factors for Child Maltreatment

Child maltreatment is a complex phenomenon. Current models of child maltreatment suggest that factors at the individual, family, community, and societal levels interact to contribute to child maltreatment.³⁸⁻⁴⁰

The factors included in the model above are typically grouped as either risk factors or protective factors. Risk factors increase the likelihood of negative outcomes occurring, while protective factors insulate individuals or families from stress and other negative influences and increase the likelihood of positive outcomes occurring.⁴¹ (see sidebar to right) Risk factors should not be viewed as direct causal links to child abuse or neglect, but rather as contributing factors. When risk factors accumulate and outweigh protective factors, negative outcomes, such as child maltreatment, are more likely to occur.⁴¹

Definition of Child Maltreatment Prevention

Child maltreatment prevention efforts include activities, strategies, or programs to reduce risk factors and increase protective factors associated with child maltreatment. These efforts are designed to increase the capacity of parents, caretakers, and communities to protect, nurture, and promote the healthy development of children. Prevention efforts vary tremendously in goals, target populations, and activities, and may take the form of public policy initiatives, public awareness campaigns, screening and assessment activities by professionals or agencies serving families, and programs, such as informal parent support groups, or intensive, multi-faceted home visitation programs, among others. One way to think about types of child maltreatment prevention efforts is to consider the population that is being targeted. Child abuse prevention programs can be universal programs, selective programs, or indicated programs (see Table 1). A strong child maltreatment prevention system will include a range of universal, selective and indicated strategies to effectively target different populations who have different needs and different levels of risk.

Risk Factors

Child Risk Factors

- Young children (under 36 months) are at the highest risk for physical maltreatment, neglect, and homicide. Pubescent children are at highest risk for sexual abuse reporting, although case histories suggest that the abuse may start earlier.⁸
- Girls are at higher risk for sexual abuse, although there are few gender differences in physical abuse and neglect.⁴²
- Children with difficult temperaments or conduct disorders have been identified at higher risk. This risk factor should be viewed with caution, however, as many children may develop behavioral problems as a result of maltreatment.^{43,44}
- Children with disabilities (physical handicaps, developmental disabilities, birth complications) have a higher probability of abuse or neglect.⁴⁵

Parental Risk Factors

- Single parenting, low-education levels, and being teen parents all seem to increase risk for child maltreatment. Maltreatment occurs among all socioeconomic levels, however, there is still relatively higher risk for maltreatment among families with low-income and low-socio-economic status.⁸
- There is a higher risk of maltreatment among parents who were past perpetrators of maltreatment or who have a history of being maltreated as a child (although two-thirds of victims do not maltreat their offspring).⁴⁶

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North Carolina's Vision for Child Maltreatment Prevention

Building upon current research and thinking of child abuse prevention scholars, the Task Force articulated a vision for a comprehensive child maltreatment prevention system in North Carolina.⁶¹⁻⁶⁷ To effectively reduce child maltreatment, state and local communities must shift attention and resources to developing systems of support for expectant families and families with young children (0.5 years).⁶¹ This is important for a number of reasons. First, the state's youngest children are at the highest risk of being maltreated; second, many parental risk behaviors that have long-term negative consequences for children's healthy development occur during these periods (e.g., smoking during pregnancy, parental substance abuse that interferes with parent/child attachment); and third, because these developmental periods offer the best "windows of opportunity" for helping families develop nurturing, responsive relationships that promote healthy child development.^{62,63}

An essential aspect of North Carolina's child maltreatment prevention system should be a strong foundation of support for

Table 1.

Population-Targeted Strategies for Child Abuse Prevention

Universal Strategies target activities to the general population with the goal of preventing child abuse and neglect from ever occurring. Universal strategies are available to everyone, rather than targeting populations based on risk factors or specific characteristics. Examples include broad-based public awareness campaigns on positive discipline, developmental screenings for children in primary healthcare settings, and postpartum home visits for all parents of newborns.

Selective Strategies target activities to a group with specific risk factors with the goal of preventing child abuse and neglect from occurring in that group. Programs may target services to individuals, families, or communities based on risk factors, such as parent age, poverty, substance abuse, domestic violence, or maternal depression. Examples include: Intensive home visitation programs for first-time, low-income mothers; parent training for adolescent mothers; respite care for parents of children with special needs; and parent support groups for single parents.

Indicated Strategies target activities to a group that has experienced abuse or neglect with the goal of preventing child abuse and neglect from reoccurring in that group. Examples include Parent-Child Interaction Therapy for physically abusive parents, parent training for parents when there has been a substantiated allegation of abuse or neglect by a local department of social services, and parent support groups for nonoffender parents of children who have been sexually abused.

RISK FACTORS—continued from page 346

- Maltreating parents often have inadequate knowledge of child development (i.e., unrealistic expectations of what children know, understand, or can do at certain ages). Other risk factors include parental beliefs and attitudes during child rearing, negative affect in the parent-child relationship, substance abuse problems, depression, and loneliness.⁸
- Child sex offenders may demonstrate cognitive distortions, lack of empathy, negative affect, poor social skills, alcohol or substance abuse problems, and deviant sexual interests.^{47,48}

Family Risk Factors

- Lack of resources, large number of children (four or more), current stressors (financial, job, health, loss of loved ones), marital conflict or violence, social isolation from other families, other family members with a history of maltreatment, and inadequate monitoring by other family members are all risk factors for maltreatment.⁸
- Family disruption, separation and divorce, or children living with mother and nonbiological father increases risk for child sexual abuse.^{49,50}

Community and Policy Risk Factors

- Neighborhoods with high mobility, unemployment, poverty, and a lack of monitoring and connectedness show greater rates of maltreatment.⁵¹
- Communities with military presence, natural disasters or crises, inadequate financing of human services, and inadequate human service coordination also demonstrate higher rates of maltreatment.⁵¹⁻⁵³

Cultural and Social Risk Factors

The risk for child maltreatment is higher in those cultures where it is the cultural norm to spank or victimize children, where corporal punishment is legally allowed, where children have poor legal status, where the understanding of child development is weak, where children are viewed as "possessions," and where the media portrayal of violence is common.⁵⁴

Protective Factors

Although the literature is not as extensive with regard to factors that protect against maltreatment, some characteristics have been identified as protecting against child maltreatment and contributing to general child and family well-being.

Child Protective Factors

Children with easy temperaments, high cognitive abilities, and competence in normative roles have decreased risk of maltreatment.⁵⁵

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every expectant family and all parents with young children.⁶¹ As Wanda Hunter describes in her commentary in this issue of the Journal, such a system might include enhanced prenatal care, home visiting programs, and parent education efforts that are seen as a normal service for all parents, as well as strategies to help families build and sustain social support.⁶⁴ But public and nonprofit programs are not the only answers. Developing strong systems of support for expectant families and parents with young children will require community and institutional support of parenting; all segments of our society, from grandparents to workplaces to healthcare providers need to implement strategies to support parents and healthy parenting. For families who experience additional stressors, such as substance abuse or a history of child maltreatment, more intensive services, such as substance abuse treatment or skills-based parent training, should then be added to the universal base of support to help them overcome stressors that place them at risk for maltreatment.^{61,65} The system should also target families for support during those periods in which child maltreatment is more likely to arise, such as the postnatal period when depression or substance abuse can impair parent-child attachment, family structure changes (e.g., loss of a parent or divorce), and the development of conflict/violence between parents.65

Table 2.

Vision for Children, Families, and Communities

For children, we envision that

Every child is nurtured, supported, and protected within a safe and stable home and community environment.

For families, we envision that

- Families recognize the rewards and responsibilities of raising children, and have access to support within their own communities for meeting those responsibilities.
- Families are able to ask for and receive timely assistance without fear of being punished or blamed.

For communities, we envision that

Communities are supported in their efforts to meet the diverse needs of families in raising their children.

While child maltreatment prevention is the goal, maltreatment prevention is placed within the larger context of positive child development, healthy parent-child relationships, strong families, and family-centered communities.⁶⁶⁻⁶⁸ A system of prevention would help all parents and children before abusive/ neglectful behaviors become established and difficult to modify. It would promote help-seeking behavior as a normal and expected activity for all parents, in addition to providing more targeted services to higher-risk families.^{61,65}

RISK FACTORS—continued from page 346

Parent Protective Factors

- Psychological health and maturity enables parents to form positive attachments to their children and to reach out to others for support. Social competence, self-esteem, and self-efficacy are parental qualities that help protect against child maltreatment.⁵⁶
- Additionally, a parent's own childhood experiences and family history contribute to the parent's ability to function effectively. The nurturing, stimulation, and appropriate care that a parent received as a child serves as an enduring protective factor.⁵⁵

Family Protective Factors

- Supportive relationships with family, friends, and neighbors are critical in helping parents navigate and overcome the daily stresses of parenting. Social support networks help parents do a better job of parenting through sharing of resources and information, offering temporary or permanent alternative shelter for children when needed, and providing collective standards of parenting behavior.⁵⁷
- Family characteristics, such as regular and consistent household routines, shared parent-child activities, respectful and trusting communication, monitoring, supervision and involvement, parent-child warmth and supportiveness, positive relationship between parents, children's participation in extracurricular school activities, and parents' involvement in religious and volunteer activities, all contribute to family wellbeing.⁵⁸

Community Protective Factors

Access to adequate healthcare, quality education, and employment services benefit adult caretakers and protect children. Families will find support for raising their children in neighborhoods where there is friendship among neighbors, watchfulness for each others' families, physical safety of the environment, common knowledge of community resources, and, perhaps most critically, a sense of "belonging," which fosters feelings of ownership and responsibility.⁵⁹

Cultural and Social Protective Factors

There is some evidence that cultures that discourage violence, support families' basic needs, and discourage physical punishment do a better job of preventing maltreatment.⁶⁰

Task Force Recommendations

The Task Force made 37 recommendations to enhance North Carolina's capacity to implement effective child maltreatment prevention efforts across the state. These recommendations are comprehensive in nature and focus on the following key issues: establishing a leadership structure for child maltreatment prevention within North Carolina; developing a comprehensive data collection system to gain a better understanding of the extent of child maltreatment and the effectiveness of prevention efforts; changing social norms so that communities are more invested in supporting healthy parenting and the healthy development of children; supporting the implementation of evidence-based practice across the state; enhancing the capacity of systems already serving families and children to focus on maltreatment prevention; and obtaining needed funds to support child maltreatment prevention programs and the priorities of the Task Force.

Of the 37 recommendations, the Task Force identified 13 priority recommendations, which would have the greatest impact on the quality and availability of effective child maltreatment prevention efforts across North Carolina and, ultimately, would lead to a decrease in child maltreatment rates. The 13 priority recommendations are discussed and highlighted below as they relate to the challenges in building a child maltreatment prevention system.

Leadership

One of the first challenges the Task Force identified was the lack of leadership at the state level to promote and coordinate child maltreatment prevention efforts within governmental and nongovernmental agencies. There is currently no state agency with programmatic authority that assumes leadership for child maltreatment prevention. While North Carolina has developed a coordinated system to respond to reports of child maltreatment, no comprehensive system currently exists to prevent maltreatment from happening in the first place. To develop leadership for child maltreatment prevention efforts in North Carolina state government, the Task Force recommended the creation of a twotiered system of leadership: a Legislative Oversight Council and an interdepartmental Leadership Team, linked by common staff who would be hired and housed within the Division of Public Health. The Legislative Oversight Council would oversee the implementation and evaluation of the Task Force plan and would ensure that visibility and attention are brought to these issues. The interdepartmental Child Maltreatment Prevention Leadership Team would have direct responsibilities to implement the Task Force recommendations and to coordinate the work of different state, local, and nonprofit agencies and organizations.

Measurement of Child Maltreatment Incidence

North Carolina needs a comprehensive data collection system to more accurately estimate the incidence of child maltreatment within the state, provide information for program planning and implementation, and inform the public and policy makers of the effectiveness of prevention efforts as a whole. North Carolina currently relies on child fatality data and the Child Protective Services Central Registry as the primary sources of data on maltreatment incidence. However, there are significant limitations to these data. As noted previously, there are good reasons to think that the Central Registry underestimates the magnitude of the problem. In addition, it only contains information on children who are maltreated by caretakers, leaving out children who are abused by noncaretakers, such as extended family, neighbors, and teachers. Further, the Central Registry has difficulty in capturing the full range of maltreatment experienced by a child (e.g., multiple forms of maltreatment may be coded as only one form in the official data). Development of more accurate and comprehensive surveillance and monitoring systems is needed to effectively design, target, and evaluate a statewide prevention system. *The Task Force recommended that the Division of Public Health work with a broad range of stakeholders in developing such a surveillance system for child maltreatment.*

Changing Social Norms

The larger social environment in which families raise children plays a significant role in the occurrence of child maltreatment. Community norms and social values influence the way in which we, as a society, support families who are raising children. While public awareness campaigns about child maltreatment prevention have been quite successful in raising awareness of child maltreatment, current research indicates that these efforts have not been as effective in changing social norms to better support families raising children and in preventing maltreatment.⁶⁹ Studies indicate that the general public does not understand prevention nor believe that it is possible to prevent maltreatment.⁶⁹ This, in part, stems from an overwhelming imbalance between media coverage of the negative aspects of child abuse and neglect compared to its coverage of potential solutions to the problem. Much of the public's understanding of child maltreatment prevention comes from the media, where child abuse is typically portrayed as a criminal atrocity and a failure of the child protection system. The focus is on horrific cases of maltreatment, leading the average American to believe that child abuse is intentional, extreme, perpetual, and not preventable.⁷⁰

Public awareness efforts for child maltreatment prevention are at a crossroads. North Carolina's messages for prevention must move beyond "recognizing and reporting" child maltreatment and must target parental and community behavior changes. The Task Force recommended that PCA North Carolina, in partnership with the North Carolina Division of Public Health, explore new messages for child maltreatment prevention and develop a campaign aimed at creating a community climate in which families are supported and strengthened, and parents can seek assistance without stigma.

The glamorization of violence within the media, the public's tolerance of violence within communities, and social norms that reinforce violent responses to problems all contribute to a climate where violence is tolerated. Societal acceptance of violence, combined with a belief that all family matters are private, undermines prevention efforts. This problem is not unique to child maltreatment efforts; it overlaps with other violence prevention efforts, such as those targeted at reducing domestic violence or violence in schools. *To address this problem, the Task Force recommended that multiple state agencies and private nonprofits work in concert to support comprehensive violence prevention activities at the state and community norms that support families and healthy child development and reduce social*

acceptance of violence as an appropriate response to interpersonal conflict.

Evidence-Based and Promising Practices

Increasingly, policy-makers, researchers, and practitioners are focusing on the use of evidence-based and promising practices in community and state efforts to prevent maltreatment. Evidence-based programs are those programs that have scientific evidence of their effectiveness in reducing risk factors, increasing protective factors, and preventing maltreatment. Although the field of child maltreatment does not yet have an extensive body of scientifically proven programs, it is critical to incorporate what is known to be effective into the practice of thousands of practitioners who work with families and children daily. Part of this challenge is to continually review the program evaluation literature, keep abreast of new findings, and identify strategies to disseminate information and training opportunities to support effective practice. The Task Force recommended that an Expert Work Group comprised of researchers, state agency representatives, and community practitioners should be assembled to identify, support, and disseminate information about evidence-based and promising programs in the field of child maltreatment prevention and family strengthening.

Numerous funding entities at the state and local levels, including public agencies, private foundations, and private businesses, fund family support and family strengthening programs. While these programs are usually well-intentioned and may seem effective, many are not evidence-based, nor have they been evaluated in a comprehensive and rigorous way. Given the limited resources available for child maltreatment prevention and family strengthening programs, it is imperative that the funding available be used strategically to support programs that have strong evidence of effectiveness. By shifting funding priorities to increasingly focus on the support of evidence-based and promising practices, North Carolina can take an important step toward better outcomes for children and families. Thus, the Task Force recommended that public and private funders should place priority on funding evidence-based and promising child maltreatment prevention and family strengthening programs. When such programs cannot be identified for a specific population, funders should give priority to those programs that are theory-based and that incorporate elements identified in the research literature as critical elements of effective programs.

The Task Force recommended that the state expand or implement specific programs with strong evidence of effectiveness in preventing maltreatment or strengthening family functioning. Some of these models include:

- The Nurse Family Partnership, an intensive home visiting program with strong evidence of effectiveness in reducing maltreatment, welfare use, subsequent pregnancies, maternal behavior problems due to substance abuse, arrests among mothers, and arrests among their children.⁷¹
- Parent-Child Interaction Therapy, a parent training program originally designed to treat children with conduct behavior problems, but is now being used to treat and prevent mal-

treatment with physically-abusive families with children ages four to $12.^{72}$

- The Strengthening Families Program, a family skills training program for elementary school children and their families designed to improve family relationships, parenting skills, and the youth's social and life skills to reduce problem behaviors in children, improve school performance, and reduce alcohol/drug use in adolescents. Although designed to prevent youth substance abuse, the program successfully reduces risk factors, which are strongly correlated with child maltreatment, and strengthens family functioning.⁷³⁻⁷⁵
- The Chicago Child-Parent Center, a comprehensive, centerbased early childhood program for low-income children in preschool through third grade (ages three-to-nine years old). Well-designed studies have shown that children who participated in the Centers were 52% less likely to be victims of maltreatment, and had higher reading and math achievement scores, had lower rates of grade retention and special education placement, were more likely to complete high school, had fewer violent and nonviolent arrests, and had fewer drop-outs than the comparison group.⁷⁶⁻⁷⁸

Enhance Systems Serving Families and Children to Prevent Maltreatment

There are already many public and private agencies and programs that serve families and children. Many of these programs could be enhanced to incorporate evidence-based or promising strategies to strengthen families, reduce risk factors and prevent child maltreatment. Some of the existing programs target pregnancy and the first years of life. Others provide services to families as the child ages. Still other programs are aimed at reducing risk factors associated with child maltreatment at a population level. Opportunities exist in each of these programmatic areas to enhance child maltreatment prevention efforts.

Pregnancy and the first years of life (ages 0-5) are important periods in creating healthy and nurturing parent/child relationships. An effective family strengthening system should begin during these developmental periods and should ensure that every pregnant woman and new family has the support and resources needed to guide their children toward success in school and later in life. For example, the Task Force recognized that North Carolina should develop a coordinated system of evidence-based prenatal and early childhood home visitation programs that provides some level of services to every expectant family and new parent. Primary healthcare providers should help support parents at risk for maltreatment through developmental screenings of children, anticipatory guidance, and effective referrals to community-based organizations. Child-care providers, with additional training, could also be enlisted to help parents understand stages of child development so as to promote their child's healthy development. And greater coordination across agencies could help ensure that caregivers and children receive appropriate and effective services.

The Task Force specifically recognized the importance of Children's Developmental Services Agencies (CDSAs) in

preventing child maltreatment. North Carolina's comprehensive, interagency Early Intervention System, Together We Grow, serves children birth to age five, who are identified as being atrisk for or having developmental issues. Children who experience maltreatment are at a significantly higher risk for developing problems, such as speech impairments, cognitive delays, and social/emotional difficulties. The same is true for children who live in high-risk households characterized by instability, violence, or neglectful parenting practices. The services provided through the Early Intervention System not only help children overcome the effects of maltreatment so that they may succeed later in life, but they also help prevent maltreatment by engaging parents in supporting their children's cognitive, emotional, and social development. New federal legislation has required the Early Intervention System to provide services to all children who have been substantiated for child maltreatment. The resulting influx of new children is significantly taxing the system. Without additional resources, the Early Intervention System will be unable to adequately serve all the children and families who are in need of services, particularly those children who are at risk for maltreatment. Thus, the Task Force recommended that the state provide additional resources to the Early Intervention System and CDSAs to serve families who are maltreating or who are at high risk of maltreating their children.

Age-Appropriate Services to Older Children: Parents will continue to need support as their children get older and face new developmental challenges, or when the family is in the midst of a crisis, such as loss of a job or divorce. The Task Force recommended strategies to increase the availability and provision of such services across North Carolina. Additionally, the Task Force recognized that agencies already serving a broad range of children and families, such as local departments of social services and the Department of Public Instruction, can incorporate family strengthening strategies into already existing services and made several recommendations to that end.

Targeting risk factors at a population level: A number of familial and environmental stressors can increase a family's risk for child maltreatment. To the extent that North Carolina can reduce these risk factors on a population basis, it can be expected that the incidence of maltreatment will decrease. Specific risk factors include unwanted or closely spaced pregnancies, adolescent pregnancy, substance abuse, maternal depression, domestic violence, and unavailable or inadequate childcare.

Parental substance abuse is strongly associated with child maltreatment. Children whose parents abuse drugs and alcohol are almost three times as likely to be physically or sexually assaulted and more than four times more likely to be neglected than children of parents who are not substance abusers.⁷⁹ National studies have found that substance abuse is a factor in one-third to two-thirds of all child maltreatment reports and in 90% of reports for families whose children are in foster care.⁷⁹ Anecdotal evidence from North Carolina child protection agencies point to substance abuse as one of the top reasons children are reported for maltreatment.

North Carolina has several programs and initiatives to address the issue of substance abuse, however, there is still a significant need in the state for substance abuse treatment services for all adults and adolescents with addiction problems. Given the high risk of maltreatment for pregnant women and parents who are abusing alcohol or drugs, effective treatment services should be a priority for this population. The Task Force recommended that the Child Maltreatment Prevention Leadership Team work with the Division of Mental Health, Developmental Disabilities, and Substance Abuse Services and other substance abuse treatment organizations to increase the number of substance abuse treatment programs, with a particular focus on gender-specific programs for pregnant women and women with children and to increase outreach to identify women in need of those services.

Research studies have found that serious depression and postpartum depression are strongly associated with maltreating behavior in mothers.⁸⁰ Postpartum and maternal depression can adversely impact a woman's ability to provide affectionate, consistent, and safe care for her child. Although screening and treatment for depression are available and effective, many women with depression who seek regular healthcare will not be diagnosed or treated for these conditions. In fact, we lack information about the prevalence of maternal depression in North Carolina or about the treatment services that depressed mothers need and are receiving. Thus, the Task Force recommended that the state Department of Health and Human Services work with professional associations and health professions to develop a strategy to assess the prevalence of maternal and post-partum depression for North Carolina women and examine the issues regarding screening, access to and availability of services for this condition.

Another risk factor is the lack of quality, affordable childcare. The lack of childcare is a tremendous stress for parents who are already juggling multiple work and family responsibilities. Many parents must make difficult decisions about leaving their children in poor quality childcare settings or leaving them alone or poorly supervised because they cannot afford to miss work for fear of losing their jobs. The growing number of working families has significantly increased the need for childcare; however, the availability of quality, affordable childcare slots has not kept pace with this need. Childcare subsidies are only provided to approximately 30% of the families who are in need of subsidies and, as of March 2005, there were 14,864 children on the childcare subsidy waiting list. To address this issue, the Task Force recommended that the General Assembly appropriate additional funding for childcare subsidies so that the state can increase the number of needy families who are being served.

Funding

Child maltreatment prevention efforts require adequate funding to assure program effectiveness. Sufficient resources are needed for program implementation, training, quality assurance, and evaluation to ensure the success of this initiative. A number of funding streams are being used to fund efforts to strengthen families or reduce risk factors. However, there is only one

source of state funding that is dedicated explicitly to the purpose of preventing child maltreatment: The Children's Trust Fund, primarily housed in the Department of Public Instruction. This is funded through a state appropriation and a fee on marriage licenses, but only produces approximately \$600,000/year to be used for child maltreatment prevention activities.⁸¹ The money is used to support a part-time administrator and funding for local prevention efforts. The Task Force recommended that funding for the Children's Trust Fund be increased (through additional fees or an income tax check-off) to have sufficient funding to replicate specific programs identified as evidencebased or promising in preventing child maltreatment or strengthening families. The Task Force also recommended that the General Assembly appropriate additional funding to replicate specific evidence-based and promising programs identified in the Task Force Plan.

Conclusions

In North Carolina, a child is mistreated every 15 minutes by a parent or caretaker. Every two weeks a child dies from abuse. Maltreatment can cause long-term consequences for the child, including negative changes in neurobiological development, adverse impacts on a child's cognitive abilities and emotional well-being, difficulty or inability to form positive relationships with other people, higher rates of juvenile delinquency, higher rates of criminal behavior (including violent crime), and transmission of intergenerational child maltreatment. Ultimately, child maltreatment has broad societal consequences for the entire population, including both human and financial costs.

North Carolina's efforts with regard to the prevention and treatment of child maltreatment are at a crossroads. The state must continue to support children who have been mistreated, while at the same time, focuses more of its resources on preventing child maltreatment and strengthening families. The North Carolina Institute of Medicine Task Force report lays out the blueprint for a new framework for these efforts so that agencies, organizations, and individuals across the state understand their roles in a unified prevention effort. Evidence-based and promising practices should comprise (whenever possible) the foundation of this system so that limited resources can be targeted to those programs and activities that have the greatest potential of strengthening families and reducing risks that can lead to maltreatment. Together, we can—and we must—work to create a system where:

- Every child is nurtured, supported, and protected within a safe and stable home and community environment.
- Families recognize the rewards and responsibilities of raising children and have access to support within their own communities for meeting those responsibilities.
- Families are able to ask for and receive timely assistance, without fear of being punished or blamed.
- Communities are supported in their efforts to meet the diverse needs of families in raising their children. NCMedJ

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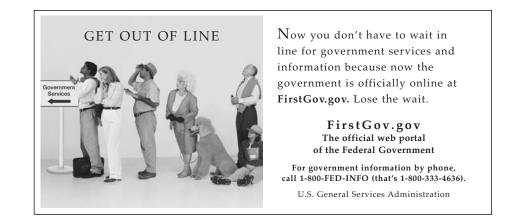
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The Impact of Maltreatment on the Developing Child

Dana M. Hagele, MD, MPH

Overview

Childhood, from infancy to adolescence, is a time of enormous neurological growth and development. Child maltreatment—including physical, sexual, and emotional abuse; neglect; and exposure to domestic violence—represents an *extreme traumatic insult* to the developing child. Specifically,

maltreatment results in disruption of the bond between child and caregiver, and it causes upregulation of the biological stress response system. Chronic traumatic exposure may then lead to persistent changes in brain structure and chemistry. Current research suggests that these biological alterations contribute to longterm physical, emotional, behavioral, developmental, social, and cognitive dysfunction seen in adults

"Recent neuroimaging studies demonstrate that neuroanatomy is significantly altered among individuals who have experienced childhood maltreatment and abuse-related Posttraumatic Stress Disorder."

who have experienced childhood maltreatment. As described by DeBellis, the "psychobiological sequelae of child maltreatment may be regarded as an environmentally induced, complex developmental disorder."¹

Child Maltreatment: Biological Pathways to Adverse Outcomes

Immediate Alterations in Brain Chemistry

The psychological trauma of maltreatment triggers the complex neurochemical and hormonal systems involved in the stress response and in emotional regulation. When a child experiences an abusive insult, in their glucocorticoid, noradrenergic, and vasopressin-oxytocin systems² are activated; this highly adaptive response allows for survival in a dangerous environment. Chronic activation, however, may result in permanent changes in brain chemistry, structure, and function. Over time, maltreated children are at risk for the development of an exaggerated response to relatively minor stress. Compounding this insult, maltreated children are forced to respond to environmental threats (family violence), rather than engaging in activities necessary for the development of complex emotional, behavioral, and cognitive functioning.

Persistent Alterations in Brain Structure and Function

Recent neuroimaging studies demonstrate that neuroanatomy is significantly altered among individuals who have experienced childhood maltreatment and abuserelated Posttraumatic Stress Disorder (PTSD).³ For example, children diagnosed with maltreatment-related PTSD have reduced cerebral volume

(prefrontal white matter, right temporal lobe, and mid-section of the corpus callosum), and associated enlargement of the ventricular system.⁴ This finding indicates significant neuronal loss, and therefore, lost potential for child growth, development, and functioning. Studies have shown alterations in the pituitary⁵ and hippocampus⁶ of children with PTSD; this demonstrates a possible link between the trauma of child abuse, resultant changes in brain anatomy, and adverse effects on learning and memory.⁷

Chronic or extreme maltreatment may result in altered neurophysiology and neuroanatomy through persistent activation of the hypothalamic-pituitary-adrenal axis (HPA) and the catecholamine stress system. For example, women with a history of childhood sexual abuse exhibit HPA-axis abnormalities (cortisol suppression following dexamethasone challenge) comparable to that of adults with combat-related PTSD.⁸ Similarly,

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children with a history of sexual abuse show evidence of higher catecholamine functional activity, which manifests as physiological agitation.⁹ Finally, children with a history of maltreatment-associated PTSD demonstrate characteristic changes in cerebral blood flow patterns,¹⁰ as well as characteristic alterations in regional activation of the brain.¹¹ These findings offer a neurophysiological explanation for the behavioral and emotional changes seen in children with histories of abuse.¹²

Child Maltreatment: Intermediate and Long-Term Outcomes

Impact on Child, Family, Community, and Society

Child maltreatment, and the associated disruption of secure parent-child attachment, represents a severe traumatic exposure comparable to that of military combat. The initial physiological and behavioral response to abuse may be appropriate and adaptive. However, if the trauma is severe or chronic, persistent changes in neuroanatomy and neurophysiology may occur, often leading to the development of psychiatric disturbance, particularly depression and PTSD. Ultimately, maltreatment and its associated morbidities predict adverse short- and long-term outcomes across physical, developmental, cognitive, emotional, behavioral, and social functional domains.

General Medical Problems and High-Risk Health Behaviors

Adults and adolescents with a history of childhood abuse, neglect, or domestic violence exposure, demonstrate nearly twice the number of serious health problems as children without these experiences.¹³ Documented medical problems associated with childhood maltreatment include: chronic fatigue;¹⁴ altered thyroid function;¹⁵ altered immune function;¹⁶ eating disorders and obesity;¹⁵ asthma;¹⁶ hypertension,¹⁷ and peptic ulcer disease.¹⁸ Similarly, these exposures increase the likelihood of high-risk health behaviors among men and women, including: a higher number of lifetime sexual partners;¹⁹ increased male involvement in teen pregnancies;²⁰ higher incidence of unprotected sex with partners of unknown HIV status;²¹ younger age at first voluntary intercourse;²³ diminished birth control efficacy;² younger age at the birth of the first child;²² and greater likelihood of becoming a teen mother.²² Similarly, childhood maltreatment is predictive of significantly higher levels of alcohol and substance abuse disorders.²³⁻²⁷

Developmental Dysfunction and Mental Health Disorders

Children with a history of maltreatment frequently demonstrate significant deficits across developmental and cognitive domains, ultimately affecting educational performance. Specifically, maltreated children demonstrate deficits in attention, abstract reasoning, impulse control, and long-term memory for verbal information.¹² Similarly, traumatic exposure is associated with significant decrease in IQ.²⁸ Due to overlapping cognitive, behavioral, and emotional symptomatology, childhood PTSD may resemble Attention-Deficit Hyperactivity Disorder (ADHD) or other learning disabilities in the classroom.

Child abuse and neglect are independently associated with the development of adolescent and adult mental health disorders. This effect is mediated, in part, through persistent stimulation of biological stress systems, as well as through the development of PTSD. Mood and anxiety disorders are most prevalent among this population;^{29,30} between one-third and one-half of all abused children meet the Diagnostic and Statistical Manual of Mental Disorders^a criteria for PTSD.³¹⁻³³ In addition to the development of mental health disorders, maltreatment is associated with the development of co-morbid personality disorders.³⁵ Overall, child maltreatment and associated comorbidities are independent risk factors for suicidal thoughts and behavior.^{35,36} By eight years of age, approximately 10% of maltreated children experience suicidal ideation.³⁷

Re-victimization and Dysfunctional Parenting

A childhood history of maltreatment is associated with dysfunctional interpersonal relations in adulthood. Compared to individuals who have not been abused, adults with a childhood history of abuse and neglect report twice as many subsequent sexual assaults, higher rates of domestic violence, and four times the incidence of self-harm.^{38,39} Chronic, severe maltreatment is independently associated with re-victimization, including later involvement in intimate partner violence.³⁹ This outcome may be mediated through the development of cognitive distortions, learned in the context of child maltreatment.⁴⁰ Similarly, child maltreatment independently predicts later dysfunction in parenting, including the perpetration of severe physical maltreatment⁴¹ and inappropriate maternal dependence on children for emotional fulfillment.⁴² These findings may contribute to the intergenerational transmission of maltreatment.

Adverse Societal Effects

Child maltreatment and associated morbidities independently predict child and familial dysfunction across physical, developmental, emotional, behavioral, cognitive, and social domains. Thus, maltreatment—both directly and indirectly has a profound, adverse effect on societal health and functioning. Specifically, child abuse and neglect are correlated with increased prevalence of public health problems, including community and domestic violence, delinquency, mental health disorders, alcohol and illicit substance use, obesity, suicide, and teen pregnancy. These outcomes, in turn, correlate with increased utilization of public and private resources. For example, individuals with childhood histories of maltreatment participate in more emergency room and general medical evaluations.⁴³ They also demonstrate higher utilization rates with regard to

a "The Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition™ (DSM IV) is the manual physicians, psychiatrists, psychologists, therapists, and social workers use to diagnose mental illness.

inpatient and outpatient psychiatric services, as well as surgical hospitalizations.⁴⁴⁻⁴⁶ In addition to direct healthcare costs, maltreatment and its sequelae result in incalculable expenditures across the child welfare, public and private mental health, early intervention and education, juvenile delinquency and criminal justice, public welfare, and public health systems.

Adverse Affect of Maltreatment on the Developing Child: Public Health Implications

Physiological and psychological response to stress, including maltreatment, is often adaptive, allowing for the preservation of

individual safety and integrity. With chronic or extreme traumatic exposure, this response may become highly maladaptive, resulting in further child and family dysfunction. Ultimately, child and family dysfunction impacts community and societal well-being. Thus, the optimal public health response to child maltreatment necessitates policies and practices supportive of evidence-based primary prevention efforts, early detection through screening and evaluation, prompt stabilization of child and family safety and well-being, and initiation of appropriate intervention and therapy. **NCMedJ**

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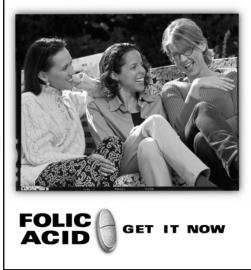
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Building an Effective Child Maltreatment Surveillance System in North Carolina

Adam J. Zolotor, MD, MPH, Brenda McAdams Motsinger, MS, RD, LDN, Desmond K. Runyan, MD, DrPH, and Catherine (Kay) Sanford, MSPH

n public health, the first step in assessment of a health or social problem is enumeration of the population affected and the impact of the problem. Estimated rates of child physical

abuse in North Carolina range from 0.5 to 36 per 1,000 children,^{1,2} a 70-fold difference. Such disparate estimates of abuse rates challenge policy makers to establish policies and systems for prevention. A child maltreatment surveillance system is needed in North Carolina that will provide for continuous and systematic data to identify the magnitude and the impact of child abuse and neglect. This will inform the allocation of resources and public health

"Emotional abuse, neglect, and witnessing domestic violence are all forms of child abuse that are harder to survey, more chronic in nature, and may cause more harm to the child than physical abuse."

action,³ and it will require leadership and responsibility within state government. In this commentary, we review the current approaches to child maltreatment surveillance, options for surveillance, and promising new practices.

A public health-based child maltreatment surveillance system must rely on coordinated efforts and a variety of data sources from multiple sectors: social services, public health, law enforcement, and academic research. One of the challenges of maltreatment laws, yet are consistent with national definitions and data elements.

developing a surveillance system lies in the definition of child

maltreatment. Currently, this differs widely among agencies and

care providers. The Centers for Disease Control and Prevention

Current Approach

The current approach to monitoring child abuse relies on reports or complaints about suspected maltreatment that are made to county departments of social services (DSSs). In 2003

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Prevention has made establishing uniform definitions of child abuse and neglect a priority for moving forward with surveillance, research, and prevention. A position statement with uniform definitions of various types of maltreatment will be forthcoming from the CDC.⁴ North Carolina's Division of Public Health needs to begin the work of designing a child maltreatment surveillance system with elements that are aligned with our child

(CDC) Division of Violence

there were 120,033 accepted reports to North Carolina DSSs; 32,846 (27%) of the accepted reports were substantiated. Due to state law and social service policy, North Carolina DSS classifies an overwhelming majority of substantiated reports as neglect (90.3%) and very few substantiated reports as physical abuse (3.1%). Of the states and the District of Columbia, North Carolina ranks last (51st) for its rate of substantiated cases for physical abuse, 46th for its rate of substantiated neglect.¹ These statistics should be interpreted cautiously as they reflect differences in state law and social service policy, not necessarily state trends in maltreatment.

The current child abuse reporting system in North Carolina is not designed for surveillance. It is designed to track the activities of the Division of Social Services and captures only those children reported to authorities. There are other important shortcomings in using DSS statistics as a surveillance system. Survey research from North Carolina has shown that rates of physical abuse may be more than 70 times the rate reported by the Division of Social Services.² County-level policies dictate the management of child abuse reports, and differences in these policies lead to variations in responses by local social services departments. Many reports are not accepted for investigation. Substantiation represents a decision by a social worker to believe the allegation of suspected maltreatment. Although rates of substantiated reports (all types) in North Carolina varied by county in 2003 from 3/1,000 children to 44/1,000 children, it is doubtful that the true rates of maltreatment vary so greatly. Cases may be reclassified from physical or sexual abuse to neglect to streamline administrative requirements.⁵ Lastly, the DSS registry captures abuse only by caretakers. Abuse by other people responsible for a child, such as care providers, teachers, neighbors, and parents' partners, is not captured in DSS reports.

Recent efforts in augmenting child abuse surveillance systems nationwide have focused on the extremes of physical abuse. These include surveillance systems of emergency department and hospital discharge records, as well as death reporting systems. Emotional abuse, neglect, and witnessing domestic violence are all forms of child abuse that are harder to survey, more chronic in nature, and may cause more harm to the child than physical abuse.^{6,7} To better understand the scope and magnitude of harm that results from child abuse and neglect, an effective system of surveillance must include the less physically obvious forms of abuse, such as emotional abuse, neglect, and witnessing domestic violence.

Opportunities for Surveillance

The national Institute of Medicine recommends an ecological approach to public health problems that include understanding and addressing the determinants of health.³ Therefore, an effective surveillance system must include data not only on an individual level, but should also include community-level measures and environmental indicators about community characteristics (policies, norms, support mechanisms) that influence behaviors, such as child maltreatment.⁸ The following describes what is currently

available at the individual level. More work is needed to identify strategies to capture community and environmental indicators that are of equal value.

Child maltreatment can be identified after an injury is sustained through reports to social services or presentation to the medical or mental healthcare system. There is potential for identifying an incident of child maltreatment if it results in recovery, disability, or death. An example of identifying recovery as a result of maltreatment would be population-based surveillance of childhood trauma experiences. An example of identifying disability as a result of maltreatment would be population-based surveillance for symptoms of childhood trauma among adolescents or young adults. Previous population-based child maltreatment surveillance systems in North Carolina and in other states have been able to obtain data on recovery and disability by asking children or young adults about childhood experience,⁹ asking potential perpetrators (parents or adults),^{2,9,10} or seeking information from systems and providers of care to children. This latter group could include physicians, hospitals, mental health professionals, educators, clergy, and social services.¹¹⁻¹³ Another opportunity for documenting child maltreatment is with the death of a child. North Carolina currently monitors the causes of death for all children through the Office of the Chief Medical Examiner and the North Carolina Child Fatality Task Force. The Injury and Violence Prevention Branch of the Division of Public Health recently improved the system for collecting information about violent deaths through the North Carolina Violent Death Reporting System (see page 403).¹⁴

Monitoring Risk Factors

One approach to an augmented surveillance system of child maltreatment is to monitor the risk factors associated with child abuse and neglect. Data about known risk factors are available from current health data sources such as birth certificates, death certificates, the Pregnancy Risk Assessment Monitoring System (PRAMS), the Behavioral Risk Factor Surveillance System (BRFSS), the Child Health Assessment Monitoring Program Survey (CHAMPS), criminal justice data, and the United States census. For example, known risk factors for child maltreatment, such as poverty, single parenthood, tobacco use, and adequacy of prenatal care, are readily available from birth certificate data.¹⁵ However, risk factors only increase the probability of an event. A prevention program may effectively reduce the prevalence of a risk factor without changing the prevalence of child maltreatment.

Monitoring the Occurrence of Child Maltreatment

Child maltreatment can be monitored through multiple sources, such as reports to social services, presentations of children to other systems of care, primary surveillance of perpetrators or victims, or through surveillance of those who work professionally with children. The challenges of using Child Protective Services data were discussed previously in this commentary under the section entitled "current approach." Other systems of care have additional or different inherent biases. For example, a hospital discharge data system and/or emergency room data system only captures those events of child maltreatment that result in hospital-based medical care. As a result, hospital-based systems often only capture physical injuries and not the more common cases of neglect and emotional maltreatment. In addition, the circumstances or the intent of injury are seldom reported, and therefore, the mechanism and manner of the injury cannot be coded. So far, these types of surveillance systems have been shown to identify only small numbers of cases not already known to social services.¹³ However, healthcare data systems may be useful in capturing information about severity and disposition that is not measured with social service registries.

Another data source is the National Incidence Study (NIS), a recurring federal survey of professionals who work with children. This important national survey gives us insight into the national patterns and changes in the occurrence of child maltreatment, but cannot provide state- or local-level detail.¹¹

In many cases of child maltreatment, only the victim and the perpetrator are privy to the incident. A recent study conducted in North Carolina asked parents about their discipline and parenting behaviors. The findings of this study indicate that 3.6% of the North Carolina parents who responded to the survey reported one or more of the following in the last year: shaking a child less than two, beating, burning, or kicking a child, or hitting a child with an object somewhere other than the buttocks.² This is 70 times the rate of substantiated abuse reported by North Carolina DSS. The study did not collect information on the intent or consequences that surrounded these acts of violence.

Monitoring Consequences

Another option for a child abuse surveillance system is to measure the consequences of abuse and neglect, such as criminal behavior rates, school dropout rates, prevalence of adolescent and adult psychiatric disease, etc. Although these types of endpoints are reasonably well-captured in North Carolina databases, no formal mechanisms currently exist to link them to antecedent events in other databases that contain information on child maltreatment.

Promising Practices

North Carolina Families Accessing Services through Technology

There are several new sources of data that North Carolina can use in building a child maltreatment surveillance system. DSS is in the process of implementing a new program called North Carolina Families Accessing Services through Technology (NCFAST). This system will use new technological tools and business practices to improve the services provided by county DSS agencies. It will also improve the consistency of data collection and allow data to be compared more easily among counties. This new system may eliminate or minimize some of the differences between the county systems of report processing. Also, for each report that is accepted to the department of social services for a family or investigative assessment, the family's needs are now assessed using a standardized risk assessment tool. Data from the risk assessment tool could be used to measure indicators, such as severity, chronicity, and co-morbid risks to the child.

Domestic Violence

It is well-documented that domestic violence is a risk factor for child abuse.⁶ Appel and Holden estimate the co-occurrence of domestic violence and child abuse at 40%.¹⁶ Research has shown that witnessing domestic violence may cause more harm to the psychological health and development of children than physical abuse.⁷ For this reason, DSS has recently implemented a policy to accept all reports of witnessed domestic violence for investigation. In addition, the North Carolina General Assembly passed a law in 2003 making acts of domestic violence committed when a child is present a separate and punishable felony for perpetrators.

Several of the state's public health surveillance systems collect information on domestic violence. For example, the North Carolina State Center for Health Statistics annually administers the Behavioral Risk Factor Surveillance Systems (BRFSS) and the Pregnancy Risk Assessment Monitoring System (PRAMS). BRFSS assessed the rates of current and past violence perpetrated by a partner, spouse, acquaintance, or stranger from 2000 to 2003. In 2003, 3.9% of BRFSS respondents reported that their current spouse or partner had been abusive to them.¹⁷ Likewise, 3.2-3.4% of women surveyed through PRAMS reported that their spouse or partner had been physically abusive to them before, during, or after their recent pregnancy.¹⁷

North Carolina Violent Death Reporting System (NCVDRS)

The Injury and Violence Prevention Branch of the North Carolina Department of Public Health began collecting information for the NCVDRS as of January 2004. This population-based surveillance system includes information on victims, suspects, their relationships, circumstance, and the mechanism of the fatal injury or injuries in every incident that resulted in a violent death. Data sources include death certificates, medical examiner records, and law enforcement reports. This system can be queried by age of victim and produce reports about the age of each child involved in a violent death in North Carolina. See page 403 for more information.¹⁴

Child Health Assessment and Monitoring Program Survey (CHAMPS)

The North Carolina State Center for Health Statistics launched CHAMPS in 2005. The Child Abuse Surveillance Sub-committee of the North Carolina Institute of Medicine's Child Abuse Prevention Task Force proposed that several questions on parenting practices and discipline be added to this tool. This is a large scale surveillance effort that will involve over 5,000 children before the end of 2005. Parents who participate in the BRFSS (a random digit-dial survey) and have at least one child are asked to participate in CHAMPS. They are asked questions about one randomly selected child concerning family circumstances, child's health status, and their parenting practices. Unweighted preliminary results from some relevant questions in CHAMPS collected during the first four months of 2005 are shown in Table 1. None of these indicators are directly equivalent to abuse or neglect. However, data from CHAMPS can add to the current surveillance system by providing information on discipline strategies, bonding, and meeting the basic needs of children.

Table 1. Preliminary Unweighted Data from CHAMPS (partial year data, N=1,438)

Question	Percent
Hurt because no adult watching closely enough last month	31.5%
Spanked last month	20.7%
Insulted by parent last month (called dumb, lazy, or similar)	4.9%
Children less than age five were home alone for more than	
one hour last month	4.7%
Didn't get all needed medical care last year	3.5%
Skipped meal because there wasn't enough money for food last year	2.0%
Data provided by the North Carolina State Center for Health Statistics	

Conclusions

It is clear that child abuse and neglect are common in North Carolina. A coordinated approach will be essential to move child maltreatment surveillance forward. Several sources of high-quality data are currently available, and important new strategies are emerging. Because of its expertise in conducting population-based surveillance in many public health arenas, the Division of Public Health is in the best position to take the lead role in developing a coordinated child maltreatment surveillance system, while continuing to work with DSS, academic partners, and state and local agencies. Potential data users, including departments of health and social services, school districts, partnerships for children, will be involved in the development of a maltreatment surveillance system. A new child maltreatment surveillance system should include standardized and linkable information gathered at the individual level, but should also include community-level measures and environmental indicators about community characteristics (policies, norms, support mechanisms) that influence behaviors such as child maltreatment. **NCMedJ**

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Risk and Protection in the Perpetration of Child Abuse

Kenneth A. Dodge, PhD

Michelle Hughes and her colleagues provide a comprehensive and accurate summary of the literature on predictors of child abuse in this issue of the *North Carolina Medical Journal.*¹ Their review is organized in layers that conform to an ecological model of the factors that lead someone to engage in abuse or neglect of a child. The factors are further organized into risk factors (those that increase the likelihood of abuse) and protective factors (those that buffer a parent from engaging in abuse). The risk and protective factor approach is commonly used in this field, but may not be familiar to the broader public. What may bring this excellent review to life is an analogy to a more publicly understood phenomenon.

Preventing Heart Attacks and Preventing Child Abuse: An Analogy

Preventing child abuse is a bit like preventing a heart attack. Using the analogy of cardiovascular disease, one can see how the study of risk and protective factors for child maltreatment may lead to innovative approaches to prevention. Cardiovascular disease is used as a model because it is familiar to most persons, has distressingly high morbidity and mortality, and has had successful prevention outcomes, which have accrued from a risk and protective factor approach. There are both similarities

and differences between child abuse and heart attack, which will help one better understand the former.

First, cardiovascular disease is a syndrome, that is, a loose collection of precursor signs that develop into symptoms which, over time, sometimes end up with a dramatic event, a heart attack. Early signs include high blood pressure and abnormal electrocardiogram (EKG) results, often without noticeable behavioral dysfunction. The developmental progression is one where these signs and symptoms worsen on a continuum, leading to a pathological process of narrowing of arterial pathways, culminating in the extreme event of a heart attack. Unlike many classic diseases for which a single pathogen is the defining characteristic (e.g., with AIDS, the defining characteristic is the presence of HIV), cardiovascular disease has no single operational definition, but instead is inferred from a pattern of nonessential, nonexhaustive, and insufficient symptoms.

So, too, it is with child abuse. The parent who ultimately maltreats a child may be identified even before becoming a parent (through risk factors, such as their own childhood of victimization). This person may display early signs of dysfunctional parenting that, if untended, can sometimes sharply catapult into a single dramatic event of child abuse or, in other cases, gradually worsen to the point that maltreatment is observed by another person and reported. There is no single indicator of the eventual abusive parent, and there are many routes to child abuse. Thus, the precursors of child abuse, like cardiovascular disease, are a nebulous array of behaviors, risk factors, and life circumstances, rather than a sharply defined disease.

A Continuum of Dysfunction

Second, cardiovascular disease is understood as being at the end of a continuum of dysfunction on which all persons can be placed. Although qualitatively distinct outcomes occur at the extreme end of this continuum (e.g., a heart attack), the continuum nevertheless suggests that the difference between normality

"If the public would come to understand that the actual difference between any parent and the maltreating parent is, in fact, simply one of degree or magnitude, then greater empathy and support for prevention of maltreatment might be generated."

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and disorder is a gradual one of degree. This connection between normality and disorder increases the public's ability to identify with the afflicted person, to empathize with her or his plight, and to provide nonstigmatizing support for the person with cardiovascular disease. We all know that we stand just a few steps away from the disorder ourselves. With child abuse, research on strategic framing indicates that much of the public views the abusive parent as one whose difficulty does not lie on a continuum that includes the public; rather, the abusive parent is perceived as a "monster" that is unlike the rest of us. Because of this distancing, the public has been relatively unwilling to support child abuse prevention efforts. If the public could come to understand that the actual difference between any parent and the maltreating parent is, in fact, simply one of degree or magnitude, then greater empathy and support for prevention of maltreatment might be generated.

Of course, some cases of cardiovascular disease do indeed represent a qualitatively different pathological disease process that is not found in most people. Likewise, some cases of child abuse involve severe parental psychopathology that is sharply different from normal behavior. Fortunately, as with cardiovascular disease, these pathological cases are rare.

Risk Factors

Third, the epidemiology of cardiovascular disease has identified different risk factors that occur at the distal and proximal levels. At the distal level, risk factors that have been identified through replicated longitudinal investigation include a fatty diet, sedentary lack of exercise, cigarette smoking, high levels of chronic emotional stress, and possibly genes. These risk factors are predictive of later cardiovascular disease over long periods of time. The relation is empirical and probabilistic, meaning both that the risk factor is not necessarily causal and that exceptional cases that do not conform to the pattern are possible. Not every McDonald's[®] hamburger lover develops heart disease, but a steady diet of fatty foods is like spinning a roulette wheel for a heart attack.

At the proximal level, the build-up of plaque in coronary arteries heightens blood pressure and dramatically increases the risk of a heart attack. This imminent risk factor is so strong that dramatic preventive intervention, such as bypass surgery, is often recommended. The relation between distal and proximal risk factors provides insight into the causal chains that lead to a heart attack: a steady diet of fatty foods increases plaque build-up, which closes arteries, which can cause a heart attack.

Distal and proximal risk factors in child abuse can be described in the same way. Distal risk factors for becoming a child abuser that are described in the Issue Brief in this issue of the Journal¹ include an early life as a victim of child abuse, dropping out of school, having a large number of closely spaced children, being a single or teen parent without adequate economic resources, lacking knowledge of child development and parenting, and being socially isolated. The parent who lives in these circumstances is statistically at risk for engaging in abuse or neglect of a child. Proximal risk factors include substance use, depression, marital violence, and acute family stress. One

proximal process in child maltreatment involves the parent who becomes consumed by substance use and, thus, neglects the child. This proximal process also is correlated with a prior distal history of a childhood of victimization, poverty, and social isolation. One (among many) developmental story moves from the distal factors of past victimization and social isolation to a current situation of high stress that triggers child abuse.

The Effects Are Cumulative

Another similarity between child abuse and heart disease is that risk factors accumulate. Research has shown that the more risk factors that one has for heart disease, the greater the likelihood of a heart attack. Similarly with child abuse, evidence has shown that the more risk factors a family has, the greater the likelihood of committing or experiencing child abuse. This relationship is probabilistic, though exceptional cases do occur. Not every lifelong smoker develops heart disease, and not every past victim of child abuse perpetuates the cycle in the next generation.

Equifinality and Multifinality

Two characteristics of heart disease are equifinality and multifinality. One person may develop a heart attack as a consequence of smoking, whereas a nonsmoker may develop heart disease as a consequence of a fatty diet. There are several independent paths to heart disease (called equifinality). So, too, the paths to child abuse are divergent. One abusive parent may follow a path from childhood victimization to current marital violence to the abuse of a child, whereas another parent may begin the course by being a single, teenage, socially isolated parent. Multifinality is the phenomenon that many of the same risk factors for heart disease also happen to be risk factors for other diseases such as lung disease and cancer. Cigarette smoking leads to heart disease in some persons and to lung disease in other persons. Many of the risk factors for child abuse also happen to be risk factors for other problematic outcomes, such as psychopathology, medical illness, unemployment, and welfare.

Multifinality is an important characteristic because it buttresses the case for prevention efforts that are targeted toward risk factors. Intervention with single, teenage parents or with couples experiencing marital violence is economically and ethically justified not only because of the link to later child abuse, but also because of links to other costly and devastating outcomes.

The Public Good of Prevention

Cultivating public interest and government support for preventive intervention has been difficult, even for heart disease, because the time lag between the occurrence of a distal risk factor and the occurrence of child abuse may be long, and the relation is merely probabilistic with many exceptions. The case for preventive intervention with heart disease has grown from empirical studies demonstrating the links between risk factors and pathological outcomes, a good simple story of how the problem develops, and economic studies suggesting that dollars (and lives) can be saved by investment in prevention. There is a public good in the investment in prevention, just as there is a public good in preventive maintenance of roads, bridges, and levees.

With heart disease, prevention occurs at the universal, selective, and indicated levels, corresponding to the type of risk factor that is targeted and the population that suffers from that risk factor. Universal interventions include taxes on cigarettes and regulations requiring listing the fat content on food packages because the entire public is at risk for smoking and eating fatty foods. Selective interventions, such as daily aspirin and other medications, are targeted toward proven high-risk persons, such as those with high blood pressure. Indicated interventions, such as coronary bypass surgery, are delivered to those who have a demonstrated pathological process such as a clogged artery.

With child abuse, the preventive interventions that are recommended by Hughes et al.¹ follow the same structure and logic. Universal interventions that are recommended for all parents include public awareness campaigns and improved screening during pediatric visits. Recommended selective interventions include intensive home visitation for (high-risk) poor, single mothers, and respite care for parents of children with special

"Many of the risk factors for child abuse also happen to be risk factors for other problematic outcomes, such as psychopathology, medical illness, unemployment, and welfare."

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1 Hughes M, et al. Preventing child maltreatment in North Carolina: New directions for supporting families and children. NC Med J 2005;66(5):343-359. needs. Finally, recommended indicated interventions include parent-child interaction therapy for first-time abusive parents to prevent recurrence.

Preventive interventions include both risk-reducing efforts and protection-enhancing efforts. Heart disease risk-reducing interventions target the risk factor directly (e.g., medication to lower blood pressure), whereas protection-enhancing interventions build strength to resist future risks (e.g., daily exercise). With child abuse, some interventions target a risk factor directly (e.g., couples therapy to resolve marital violence), whereas others promote protection by building strengths (e.g., parenting skills training).

With heart disease, we have recognized that not all prevention can or should operate at the individual level. Government efforts to get food-processing corporations to decrease the fat content of foods through regulation are as important as efforts to get individuals to stop purchasing these foods. The public at large, and government, have taken on the task of reducing the overall rate of heart disease because it will prove cost-beneficial. What is needed is a more concerted effort to get the public and government to take on the task of reducing the population rate of child abuse and not to rely solely on efforts to help individuals refrain from abusing children.

Summary

In sum, the adoption of a risk and protective factor approach to understanding and preventing child abuse is highly consistent with empirical study of how child abuse develops and with efforts in the prevention of heart disease. This analogy can be helpful in designing a comprehensive approach to the prevention of child abuse. It should not be taken too far, however. For example, it may be destructive to perceive abusive parents as "sick." There may be better metaphors that do not invoke sickness, such as literacy. So, the analogy would go like this: abusive parents are like illiterate adults, and prevention of abuse will require a universal comprehensive, life-long, public education system that includes years of focused education for all, coupled with a selective special education system for high-risk individuals. **NCMedJ**

Reframing the Issue: A New Child Maltreatment Prevention Message

Becky A. Wrisley

orking with the media to mobilize the public in efforts to prevent child maltreatment has long been regarded as a vital component of a comprehensive child maltreatment prevention system.¹ Public awareness activities play an important role in that they have the potential to reach diverse audiences parents, professionals, community members—who are critical in protecting children and supporting families.

Since the 1970s, child maltreatment prevention professionals have been implementing prevention campaigns across the country. Overall, they have been tremendously successful at making an issue out of child maltreatment and bringing it to the forefront of the public's concerns. However, child maltreatment prevention public awareness efforts have become frayed and repetitive. Campaigns swing wildly from showing or implying graphic maltreatment to heartfelt messages trying to increase the "value" of children in parents' eyes.

History of Child Maltreatment Public Awareness

There is little research or collected history of child maltreatment prevention public awareness campaigns. However, we know that as early as the 1870s, child maltreatment showed signs of growing in the public's consciousness. The "rediscovery" of child maltreatment occurred in the 1950s-1970s, an era when equity and social responsibility dominated public discourse.² Until this time, and still existing across many areas of our culture today, children were inherently viewed as property of the family. The 1962 article, "The Battered-Child Syndrome," by C. Henry Kempe served as a springboard for child maltreatment to reassert itself as a powerful social issue.³

Between 1963 and 1967, every state passed some form of child maltreatment reporting laws. However, little was done to educate the public about these laws. Public awareness campaigns about child maltreatment began being launched to improve professional and public awareness of child maltreatment and the reporting laws. At the same time, technology in the form of Wide Area Telephone Service (WATS) lines and toll-free numbers "We must develop new child maltreatment prevention messages messages that empower people to make changes in their own behavior and support changes in the community..."

allowed professionals and concerned citizens to make long-distance calls to file reports of suspected abuse.⁴

The first public awareness campaigns consisted of messages informing the public that child maltreatment was bad, it needed to be reported, and happened all the time. Child maltreatment became a problem "sufficiently disturbing" enough to warrant public intervention. As campaigns evolved, the messages changed slightly. These messages included reporting suspected maltreatment; encouraging children to self-report; focusing on statistics about maltreatment, and featuring shocking stories/images of severely maltreated children. Fueled by public awareness campaigns and popular media attention to the issue, public outcries resulted in an expanded service system for victims and their families.

Since the 1970s, public service campaigns have effectively raised awareness of the existence of the problem, from less than 10% to greater than 90%. Nevertheless, they have been unable to convince the public that prevention is possible or to motivate positive behavior change, either individual or societal, in support of prevention.⁵

In recent years, public awareness campaigns have grown more sophisticated and strategic. However, the vast majority of

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public awareness campaigns are still designed around the notion that if you give people enough information about a topic, they will voluntarily change their behavior. Behavioral research has shown us the flaw of this thought pattern. While a certain amount of "public horror" relative to child maltreatment was necessary in the early years to create public awareness, the resulting model adopted by the public has become one of the largest barriers to advancing the issue further in terms of individual behavior change, societal solutions, and policy priorities.⁶

Following decades of public awareness campaigns about child maltreatment and neglect, the public is largely aware of the reality of child maltreatment and has an idea, sometimes exaggerated, of the pervasiveness of varying types of maltreatment. Garnering new headway and public attention for prevention will take more than relying on the traditional strategies and messages of the past.

Reframing the Issue

In early 2003, Prevent Child Abuse (PCA) America undertook a unique project to examine public opinion, communications research, and media coverage to strategically reframe the issue of child maltreatment. The goal was to identify effective communication strategies to use when talking about child maltreatment. Many social issues, such as teen smoking, breastfeeding, and drunk driving, have used strategic reframing and social marketing with great degrees of success.

Collaborating with the FrameWorks Institute, PCA America performed a strategic frame analysis. The components of the research conducted by FrameWorks Institute and its partners at Public Knowledge and Cultural Logic consisted of a meta-analysis of existing public awareness, in depth interviews, focus groups, news analysis, and talk-back testing.⁶

Six focus groups and multiple interviews were conducted to help determine the public's frame of reference on child maltreatment and neglect. These groups consisted of a diverse group of community members, including a variety of ethnicities, ages, socioeconomic statuses, education levels, and experiences with parenting. The findings from the focus groups and interviews include:

- Americans picture the worse case scenario when asked to describe child maltreatment. They believe child maltreatment is intentional, extreme, perpetual, and most often done by a parent dealing with issues such as substance abuse.
- Most Americans perceive children and teens as rude, wild, and without a strong sense of right and wrong. They believe being a parent today is much harder than in years past; however, most also believe that parents are doing a poor job at raising their children.
- A significant proportion of the public is misinformed about child development, and many adults define appropriate parental behaviors (e.g., picking up a three-month-old every time they cry) as "spoiling."
- Americans believe that parenting is an extremely important responsibility. However, the public believes few parents are prepared for the responsibilities of raising children.
- The public understands and believes that there are severe

consequences of child maltreatment and believes that children who experience maltreatment will grow up to become abusive parents themselves.⁷

Americans see child maltreatment as a very serious problem, and they believe implementing prevention activities is extremely important. However, they cannot clearly define prevention, nor do they believe they can do anything to truly affect child maltreatment.

Media Analysis

In public opinion polls conducted for *Child Trends*, approximately 3,000 Americans were interviewed about their beliefs on children and parenting. More than 60% of respondents reported that their views on children and teens were shaped by what they learned from the government, advocacy organizations, universities, and research organizations. At the same time, 68% reported that religious and community leaders influenced their views to some degree.⁸

FrameWorks Institute completed a literature review of child maltreatment and neglect in the news media. The news analysis was based on news articles and television news stories provided by Prevent Child Abuse America and supplemented by a search conducted by the Center for Communications and Community at the University of California, Los Angeles (UCLA).⁹

There are several patterns in news coverage of child maltreatment and neglect. The media analysis showed that child maltreatment is often covered as a criminal atrocity, a conflict between discipline and maltreatment, a failure of child protective services, and having a focus on child sexual maltreatment.

More often than not, the media covers child maltreatment when a horrific case has been brought to the public's attention. Findings in the public opinion polls conducted for *Child Trends* show that three-quarters of respondents reported that their perceptions were shaped by the news media.⁷ Considering the current media coverage pattern, prevention advocates have a considerable challenge ahead in reshaping the media's child maltreatment agenda.

Public Awareness Campaigns

There are two types of public awareness campaigns campaigns that work to create public will about an issue and campaigns that work to change an individual's behaviors. Public will campaigns seek to motivate the general public and public officials to take action about an issue. Behavioral change campaigns seek to change individual behavior in order to improve individual and societal well-being. Child maltreatment campaigns have taken both tactics with varying degrees of success.

Traditionally, professionals have created messages about child maltreatment prevention from an "expert" standpoint. We have been operating under the flawed pattern of thought that if we raise enough awareness about child maltreatment, people will automatically support the issue and change their behaviors, even though we are not telling them specifically what or how to change. Strategic framing and social marketing are two strategies, which have been implemented with regard to a wide cross-section of social issues with great degrees of success.

Strategic framing is an approach to communications that uses the public's deeply imbedded beliefs/views and research on the way people think to create messages. The way the story is told, including the choice of narrator and the way the message is framed, determines whether we view the story as a personal or community problem. When framing messages, one must carefully consider the audience, the narrator, any visuals in the message, and how the message is marketed.

Social marketing is the use of commercial marketing techniques and strategies to promote the adoption of a behavior or value that will improve the health or well-being of the target audience or society as a whole.¹⁰ There are three strategies used in social marketing to motivate behavior change by convincing (education), by enticing (marketing), and/or by coercion (law).

Public Awareness Recommendations

After reviewing all of the research on public opinion, media representation, and campaign evaluations, there are a number of recommendations that can be discerned for future public awareness efforts. As we work to revise our communications strategies, some of these recommendations will be easier to adopt than others.

Future campaigns need to focus on educating the public about child development, and they need to utilize messages that focus on increasing parental support in local communities. Parent information campaigns need to be targeted to all types of parents, not just abusive parents.¹¹ These campaigns need to start promoting short-term instead of long-term benefits focusing on such short-term benefits, such as less family stress and better-behaved children. Messages need to connect families to communities in positive ways to build community responsibility for kids. These messages should also help the community remember the ways in which they interact with families and the importance of families in raising children.

Campaigns need to help the public admit that parenting is a tough job—one that does not come naturally.¹² Messages

need to use strength-based language and focus on the positive factors of family life. When communicating directly about child maltreatment, campaigns should focus on situations in which many parents find themselves (e.g., divorces, unemployed, stressed, etc.) and connect parent education and family support to these situations.¹²

The media need to be carefully and strategically educated on child maltreatment prevention and new messages about positive parenting, child protection, and family support should be blended into existing media outreach efforts patterns.

A full list of recommendations for communications planning and message development can be found in the Prevent Child Abuse North Carolina publication "Reframing the Issue: Advice to Professionals on Child Abuse Public Awareness Campaigns" available at: www.preventchildabusenc.org.

Conclusion

FrameWorks Institute summed up our public awareness challenge quite succinctly, "Stop fighting the fight we've already won."¹² For more than 30 years, we have been working to raise the public's awareness of child maltreatment and neglect, and we have done just that. Reporting rates continue to climb each year, and the public demonstrates a 90% awareness rate of child maltreatment and neglect. However, continuing to promote the same messages risks alienating segments of the public.

In the next 10 years, the field of child maltreatment prevention will change radically. Already we see copious amounts of research on programs that truly make a difference, and communities across the country are reevaluating their child maltreatment prevention efforts. Public awareness must change along with programming. We must develop new child maltreatment prevention messages messages that empower people to make changes in their own behavior and support changes in the community; messages that encourage supporting parents, protecting children, and building communities. It is time for our messages to make the transition from raising awareness to stimulating behavioral and normative change. **NCMedj**

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The Role of Primary Healthcare Providers in Preventing Child Maltreatment

Marian F. Earls, MD, FAAP

Healthcare providers who care for children have long realized that to be effective, medical care must include consideration of the child in the context of the family, school, and

community, but the concept of a broadly defined "medical home" has gained increasing emphasis in recent years. The American Academy of Pediatrics defines the medical home as "primary care that is accessible, continous, comprehensive, family-centered, coordinated, compassionate, and culturally effective."¹

By providing a medical home for children and their families, primary care providers have the potential of playing a significant role in the prevention of child maltreatment. The strategies

inherent in the medical home principles closely mirror child maltreatment prevention strategies. Realizing the full potential of these prevention strategies, however, will require an increased awareness of protective and risk factors for maltreatment among primary care providers. Most primary care providers are trained to recognize abuse or neglect once it has already occurred, but strategies for early prevention have not been a focus of their training. With the recent promotion of a medical home becoming the standard of practice, now is the time to focus on prevention.

The Longitudinal Relationship with the Family

An essential component of providing a medical home is the establishment of a longitudinal relationship with the child and her/his family. This is a dynamic relationship that engages parents as partners in the care of their child. It begins early, eliciting family strengths and weaknesses and screening for risk factors

"The critical value of a medical home to a child and family is its connectedness in the community and other sources of care."

and supports. This relationship communicates an openness to discussion of concerns or issues as they arise. From the beginning of well-child care, interactions with the medical care home are built on communication about the whole child—in the family and in the community (child care, school, etc.). The primary care provider utilizes screening for: (1) psychosocial risks and

strengths and (2) the child's developmental and social-emotional skills. Screening is not a one-time event, but is done periodically over the course of the relationship (surveillance), building on the communication exchange. Research has given us good information about the 40 assets (internal and external) for children that optimize success and about factors that put children and families at risk.² Awareness and early recognition of these factors allows for early intervention and prevention of unwanted outcomes.

New Visions for Well-Child Care

Both national and state initiatives are directed at this approach to practice.^a In addition, Bright Futures^b is currently being revised with an emphasis on screening and preventive care, being family-centered, and addressing development and

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a Both the American Academy of Pediatrics and the American Academy of Family Practice have adopted and encouraged the medical home concept for several years now.

b Bright Futures is an approach dedicated to the principle that "every child deserves to be healthy, and that optimal health involves a trusting relationship between the health professional, the child, the family, and the community." For more information visit: http://brightfutures.aap.org/web/.

behavior. There is great interest on the part of the AAP, the American Board of Pediatrics, the Commonwealth Fund, and others in redefining and redesigning well-child care and the periodicity schedule to be more reflective of children's developmental needs.³ The Substance Abuse Mental Health Services Administration, the National Institute of Mental Health, the Centers for Disease Control and Prevention (CDC), and Children and Adults with Attention-Deficit/Hyperactivity Disorder co-sponsored a national conference in April of 2005 to call for early screening and identification of social-emotional problems among children in primary care practices. The CDC has a national campaign, "Learn the Signs, Act Early," encouraging primary care providers and parents to screen for developmental and social-emotional issues.

In North Carolina, the Assuring Better Child Health and Development (ABCD) project is in its fifth year. Originally funded by the Commonwealth Fund, it has resulted in a statewide Medicaid policy of using a validated, standardized screening tool for development and behavior periodically at specific well-child visits from birth to five years. Anticipatory guidance materials for parents have been developed in the project, and local and state-level networking has been established for referrals and interventions. Social-emotional screening and maternal depression screening has been incorporated in many counties.

Early Screening for Assets and Risk Factors

The primary care provider has the role of recognizing a family's assets and risks and supporting them in optimizing success. Family assets include support from other adult family members, shared family activities and values, connections in the community, parent involvement in child care or school, living in a safe neighborhood, and opportunities for stable employment. Knowledge of risk factors is also key. These are common to several important outcomes. Poverty, maternal depression, domestic violence, and familial substance abuse are all risk factors for developmental delays, social-emotional disorders, and for maltreatment. The primary provider is generally a trusted professional, who by virtue of the well-child visit schedule, comes into contact with the child and family with some frequency. The medical home then, is a very likely and appropriate place for screenings to take place. The primary care provider, who sees the family on a regular basis with the child, is in a unique position to facilitate limiting the impact of risk factors.

Discussing assets and promoting connections for support should be part of early conversations with families, along with open discussion regarding risk factors. When psychosocial screenings reveal risk, the office is the source for initial discussion and referral to community resources. This assumes previous networking by the practice with community partners and a working knowledge and connection to community providers, such as counselors, agencies, Early Intervention, child care, schools, etc.

Psychosocial screening includes asking about family relationships, maternal depression, domestic violence, and substance abuse.⁴ There are brief screening tools regarding these individual issues and general tools that address all of these topics. Other questions regarding stable housing, financial resources, and insurance coverage are also pertinent. The practice can assist families with contacting community agencies and with applying for Health Choice or Medicaid. In a family-centered practice, financial issues need to be considered for each family in order for a plan of care to be realistic and possible (e.g., for covering the cost of medication, transportation, or a referral).

Developmental and behavioral screening, completed by parents and reviewed by the provider, allow early identification of potential problems or delays. Of equal importance, screening also reviews appropriate expectations at a given developmental age, facilitating understanding regarding the child's behavior and potentially facilitating appropriate use of discipline strategies by parents. A conversation about the screening identifies the child's strengths and weaknesses, gives a template for anticipatory guidance, and elicits and respects parental concerns. In this way, parental self-efficacy and confidence are promoted. Encouraging parents to share age-appropriate books with their children from an early age has benefits for their relationship and helps develop language skills and success for early reading skills.

Children found to be at risk through screening can be referred to to Early Intervention (the Children's Developmental Services Agency). For a parent whose child has a medical condition or developmental problem, a connection to the Family Support Network can provide parent-to-parent support. Parents surveyed in the the North Carolina ABCD project indicated that participating in developmental screening allowed them to learn about typical development and to understand their own child's behavior better. The potential here for reducing abuse and neglect is obvious.

Opportunities for Intervention in the Medical Home

Maternal depression may have many ominous consequences for a child, which make screening and assistance for this disorder an important role for the child's primary care provider. The most significant of these is attachment disorder, which has dire prognoses for the child, including social problems and conduct disorder. Attachment problems have a major impact on socialemotional development in the child. In infancy, problems with social relatedness can contribute to feeding problems, which can compound the problems of attachment with a mother who has depression and can reduce her interest in feeding time with the baby. Failure to Thrive can be the result of this cycle, adversely affecting the infant's brain development and adversely impacting later learning and development.

Colic in an infant can also exacerbate attachment issues and/or can create significant parental stress. There is a typical peak of increased crying and fussiness in most babies at about six weeks of age, which finally resolves at about three-to-five months of age. For some babies, this is more prominent, and in an already stressful social situation, the risk for maltreatment is increased. The outcome of colic can be increased family interaction problems and depression. Indeed, there is a peak incidence of shaken baby syndrome associated with the age at which colic occurs.

Parents bringing home a premature infant who has had a complex neonatal intensive care unit course, may initially be faced with caring for an infant who is easily overstimulated and has poor state control. The infant may be difficult to feed and may not have predictable responses to affection or stimulation. While this is generally temporary, its duration can vary, presenting a challenge for parenting and often leading parents to question their own capability.

Anticipatory guidance that addresses these issues in a timely fashion and an atmosphere of openness to parental concerns are tools that a primary care provider can use to prevent child maltreatment. Utilizing well-child care to focus on the child in the family, employing screening tools, and making the discussion of sometimes uncomfortable topics a routine matter, establish the practice as a resource for information, support, referral, and connection to other community providers.

Early empowerment for parenting has implications for longterm outcomes, including readiness to learn, school success, and social success. The primary care home supports parenting by sharing information about appropriate expectations and discipline, facilitation of developmental skills, and promotion of the developing child-parent relationship. Early identification of risk and coordination of interventions must be timely, if prevention of maltreatment is the desired result. "Wait and see" is not only ineffective, but is actually detrimental. For example, in the case of maternal depression and attachment disorder, waiting to intervene until the child is 18 months-to-two-years old may be too late. Treatment needs to be for the dyad: therapy and/or medication for the mother and intervention for the motherinfant relationship. Referral to the Children's Developmental Services Agency for Early Intervention services will provide modeling for interaction with the child and for appropriate developmental stimulation. In North Carolina there are now

community-based mental health providers who are directly enrolled with Medicaid and receive referrals from primary care providers. In many instances they are co-located with primary care practices. Availability of such referrals reduces the stigma families often associate with mental healthcare.

The Medical Home and Networking with the Community

The critical value of a medical home to a child and family is its connectedness in the community and other sources of care. The primary care home itself is not sufficient without community partners. The characteristics of a medical home described thus far are focused on partnership with the family, include periodic psychosocial screening, and utilize specific screening for maternal depression, child development and behavior, substance abuse, and domestic violence. When concerns arise or screens indicate a child is at risk, primary care providers cannot be experts in all areas. They can be a resource for referrals for further assessment and interventions, a partner in finding information, a sounding board, and a facilitator to negotiate the system. To this end, activities for the practice to network with other community providers, establish actual contacts rather than just a phone list, and have staff designated to communicate with these contacts, make the process of referral more likely to be successful. The process is more family-centered and more satisfactory to both the provider and the family.

Measures to prevent child maltreatment are an inherent part of the medical home concept, in that the prevention and riskscreening activities are consistent with maltreatment prevention strategies. The task now is to realize the characteristics of the medical home in all primary care practices by improving office processes and by informing and encouraging families to seek medical home characteristics and processes. **NCMedj**

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A New Paradigm for Child Protection: Begin at the Beginning

Wanda M. Hunter, MPH

The Merriam-Webster dictionary defines "protection" as the act of shielding from harm. Yet, for most of us, the words "child protection" conjure up an image of a child who has been abused or neglected, because in the United States, as in most developed countries, society does not get involved in "child protection" until maltreatment is suspected. The papers in this issue of the *North Carolina Medical Journal* consider whether it is possible to really protect children from ever experiencing abuse or neglect by their parents or other trusted caregivers. Is it possible to begin at the beginning, that is, at the

time of pregnancy and birth to protect new lives and provide strong public support for the healthy upbringing of all our children?

Those of us who work in the field of child maltreatment realize that among the most important barriers to prevention are strong societal norms about family privacy and parental rights. While we may no longer believe that children are the "property" of parents to treat as they please, we do believe that children are solely the responsibility of their parents and that society should not intervene until evidence of abuse or neglect is reported.

This is when the state develops an interest in child protection because we believe that it is inappropriate to get involved until we know there is a problem. Is it possible to change this norm?

One might argue that we are already doing so. In the last 50 years, there has been a consistent move toward societal intervention to protect the physical health of pregnant mothers, infants, and children through emphases on prenatal care, screening for perinatal health problems, regular well-child visits, required immunizations, and laws stating that infants and young children must be properly restrained during vehicular transport. These policies and standards are less often viewed as intrusive and increasingly viewed as societal expectations related to assuring the well-being of pregnant women and young children.

Historically communities have informally set acceptable

standards of care for children that were communicated and enforced by extended family members and neighbors. Changes in family structure and patterns of mobility have now isolated most families from the informal helping networks that once aided parents in the care and nurture of their children, while also transmitting messages related to minimal standards of care. Yet, humanitarian and economic concerns still dictate an interest in bringing up strong and healthy children who will realize their potential and contribute to society. Preventing mental and physical health problems among children who may ultimately

"The earliest years of life are accompanied by the highest risk for physical abuse and neglect and almost all fatalities due to child maltreatment occur in the first three years of life."

> become a drain on community resources or possibly spread illness to others benefits us all. But we are not adequately protecting children or communities if we continue to address child maltreatment only after it has occurred. Preventing child maltreatment will necessitate a shift in policy toward maximizing and normalizing early assistance to parents to support family environments that nurture and protect children from physical and psychological harm.

Critical Period for Prevention

Pregnancy and early childhood are critical periods for attending to the needs of new parents and promoting the health and development of their newborns. The earliest years of

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life are accompanied by the highest risk for physical abuse and neglect, and almost all fatalities due to child maltreatment occur in the first three years of life.¹ This is also the time when the quality of care and nurturing has the greatest impact on subsequent development. Neglect and trauma experienced during the first years of life have far-reaching and often irreversible consequences.^{2,3,4} Yet, caring for infants and young children is a challenging endeavor, even for those who are well prepared. All expectant and new parents require special attention and support during the perinatal period. Some parents who are at higher risk for poor parenting will require more help. Child maltreatment and a host of other social problems could be substantially reduced if all parents were given the help they need starting during the prenatal care period and continuing for as long as the need exists.

What Do Parents Need?

Extensive research examining the impact of parenting on child health and development suggests at least four areas in which primary prevention efforts should be focused: (1) providing basic parent education about normal child development and effective childrearing strategies; (2) enhancing social support and community connectedness; (3) addressing current psychosocial risk factors, such as maternal depression, parental substance abuse, and intimate partner violence; and (4) assuring sufficient economic resources to meet the basic needs of families.

Basic parent education. Parenting practices have serious and lifelong effects on child development and well-being,⁵ but very few of us receive any training in parenting, other than what we learned in our families of origin, which runs the gamut from exceptionally good to exceptionally poor. Lack of parenting skills and knowledge about normal child development, unrealistic expectations of a child's capabilities, and ignorance of successful strategies for managing a child's behavior are all associated with child maltreatment.⁶

Social support and community connectedness. Research has shown that mothers with low social support are at higher risk of maltreating their children.^{7,8} At an ecological level, neighborhoods with high rates of maltreatment are characterized by social impoverishment, with fewer social exchanges and lower use of community resources.⁹ Social support may include close and nurturing relationships, availability of help on short notice, and participation in supportive groups.

Psychosocial risk factors. As detailed in the Issue Brief by Hughes et al.,¹⁰ research has identified a number of risk factors for poor parenting and child maltreatment that exist at every level. Maternal depression, substance abuse, and intimate partner violence are especially strong risk factors¹⁰⁻¹⁸ and the prevalence rates for these conditions during pregnancy are not insignificant. Reported depression rates in pregnant women and new mothers have been found to range from 8%-28% with poor women manifesting the higher rates;¹⁹⁻²² substance abuse rates are estimated at 11%;²³ and prevalence rates for intimate partner violence rates reported in studies where questions about violence were

asked more than once.²⁴ We know that no single risk factor results in maltreatment, but as risk factors accumulate and interact, the risk for child abuse and neglect increases.¹¹ Unfortunately, these three conditions frequently co-occur.¹⁵⁻¹⁸ Developing effective services to identify and reduce depression, substance abuse, and intimate partner violence in pregnant women and new mothers is an important prevention strategy.

Insufficient economic resources. We have long known that health problems predominate among the poor. Child maltreatment is no exception. According to the third National Incidence Study, children from low-income families (i.e., annual incomes <\$15,000) were over 22 times more likely to experience some form of abuse, as compared to children from families with annual incomes above \$30,000 per year.²⁵ Studies consistently have found child maltreatment rates to be higher among those with low education, low income, and unemployment.²⁶⁻²⁹ Factors that have appeared directly related to maltreatment (e.g., maternal depression, substance abuse, low education, single parenthood, lack of social support) are all related to poverty.³⁰ Neighborhood researchers have found that communities in which maltreated children live are seriously disadvantaged and often dangerous.³¹ State-level data confirm this relationship. A recent study examining relationships between state socioeconomic indicators and substantiated child maltreatment found a significant positive association between poverty rates and the number of substantiated child maltreatment reports, and a negative association between the generosity of state welfare benefits and state rates of neglect and foster placements.³²

Services for Expectant and New Parents

Currently we have a number of services in North Carolina to address the needs of expectant and new parents. The problem is that the best evidence-based services are not widely available, and the services that are widely available lack the resources and intensity to address the need. In addition, special efforts to address family needs during pregnancy and in the first years of a child's life are not normative and thus, may be stigmatized. For many parents, enhanced preventive services provided in routine prenatal care and well-child visits would provide the guidance and support necessary. For others, additional services delivered through home visiting and parent support groups would provide additional opportunities for developing skills and social support, while addressing parental or family problems that place children at risk. A coordinated community approach that avoids duplication of services and service gaps, while reducing the number of "providers" with which families are required to interact is ideal.

Enhanced prenatal care. Prenatal care provides an opportunity to not only monitor maternal and fetal health and prepare for childbirth and delivery, but to activate a comprehensive system of support to prepare expectant mothers and fathers for the joys and challenges of parenthood. Pregnancy is an opportune time to begin training in normal child development and parenting skills. It is not uncommon for expectant parents to enroll in prenatal classes. Most of these focus on preparing for childbirth and teaching some very basic skills related to newborn care. Such classes could be expanded to begin basic parent training in infant development and care. For example, learning about peak periods for infant crying and practicing strategies for coping with a crying baby may give parents more confidence in facing such situations and reduce the occurrence of shaken baby syndrome. Parenting classes can address issues related to social and community support, while providing a new support network consisting of the class members themselves.

It is also important to identify and address psychosocial risks that jeopardize the pregnancy and the health and development of the newborn as a part of prenatal care. The best methods for determining the level of risk and providing expectant parents with effective treatment are still being explored, but it is clear that many pregnant mothers do not divulge such problems out of fear of being reported to some authority or deemed unfit for parenthood.³³⁻³⁴ Finally, there is the issue of how to address identified problems. Screening serves no purpose and may do more harm than good if accessible and effective treatment or support options are not readily available.

In North Carolina, some enhancements in prenatal care are being realized for the Medicaid population. The Division of Public Health (DPH) now requires that all prenatal care delivered in health departments include screening for maternal depression, substance abuse prevention, and intimate partner violence. In addition, Medicaid-reimbursed prenatal care works closely with the Maternity Care Coordination Program (a component of the Division of Public Health's Baby Love services) that provides pregnant women with case management services related to a variety of concerns, often through referrals to community services. Yet, services to address identified concerns vary widely across the state. Parenting education during the prenatal and postpartum periods, once funded by Medicaid, is no longer reimbursable. It is unknown to what extent prenatal care in the private sector is addressing psychosocial risks and the need for parenting education.

Enhanced well-child visits. Pediatric healthcare practitioners can play an important role in family support during the early years of a child's life through provision of preventive services during regularly scheduled well-child visits. Like prenatal care, primary pediatric care settings are normative health-promoting environments that all parents are expected to frequent. Yet, in a national survey more than 94% of parents reported unmet needs for parenting guidance, education, and screening in visits with pediatric clinicians.³⁵ More significantly, among a Medicaid population, only one-fifth of children received preventive and developmental services that met a basic standard of care.³⁶ Extensive modifications have been called for in well-child visits to better address identified needs for parental education and attention to psychosocial problems, as well as to perform routine developmental screenings of young children to identify problems as early as possible.37 Significant, but not insurmountable, barriers exist to achieving the systemic changes that would be required to provide preventive care services that address more than childhood diseases. A recent UNC School of Medicine project, Linkages for Prevention, demonstrated that system-level changes in pediatric preventive care, which included family-level interventions and improved links to other community

services, are achievable and result in positive family outcomes.³⁸

North Carolina is fortunate to have the benefit of the Linkages project and two additional innovative ventures into improved delivery of preventive pediatric services: the Assuring Better Child Health and Development (ABCD) Project and Healthy Steps.

ABCD, a Medicaid-based program that was first piloted in Guilford County, is structured to address the health, social, and developmental needs of children through five components: (1) routine developmental screening, (2) teaching parents about healthy development, (3) identifying and responding to family concerns, (4) securing local community involvement in the delivery of developmental services, and (5) integrating services to assure the best use of resources.³⁹ An early intervention specialist supplements the work of the healthcare providers by conducting home visits to address family concerns and needs for parent education. ABCD is gradually spreading across the state as practices incrementally add components of the model. Medicaid now requires developmental screenings for all pediatric patients and is piloting maternal depression screening in some of its networks.⁴⁰

Healthy Steps, another promising program being implemented in pediatric practices in 14 states, incorporates preventive, developmental, and behavioral sciences into well-child care for children from birth to age three.⁴¹ Similar to Linkages and ABCD, Healthy Steps supplements pediatric practice with a child development specialist to assist with monitoring development and responding to parental concerns. Healthy Steps sites in North Carolina are in Chapel Hill and Lumberton. Significantly, Healthy Steps is also attempting to change pediatric practice through medical education. The Healthy Steps Residency Training program is now being implemented in all four North Carolina medical schools.

Home visiting programs. Home visitation has emerged as one of the most promising strategies for preventing child maltreatment and other poor family outcomes.^{42,43} Regular visits to the home provide an opportunity to learn about family's day-to-day functioning, cultural beliefs and affiliations, strengths, and problems. Furthermore, many families feel more comfortable and empowered in their own homes than in clinic or office settings.

A number of home visiting models have been developed and tested with varying results. Models, such as the Nurse-Family Partnership Program⁴⁴ and Project SafeCare^{45,46} that have demonstrated success in reducing poor maternal and child outcomes, including child maltreatment, tend to be more intense (in terms of frequency of visits and program duration) with well-trained personnel and structured protocols for developing parenting strengths, building social support, and addressing risks. Fidelity to implementation standards can be crucial to success. In addition, tailored approaches to link the most high-risk families with specific services or treatment plans may be necessary. The absence of successful strategies to identify and address mental illness, substance abuse, and domestic violence have been shown to undermine efforts to reduce child maltreatment.^{47,48} Home visiting programs, scattered throughout the state, comprise a number of different models. The only current Nurse-Family Partnership program is in Guilford County. There are a number of Healthy Families programs, a paraprofessional-based model that aims to prevent child abuse and neglect by improving family functioning, in general, and parenting, in particular. Programs are given flexibility in service delivery and evaluation results have been mixed.⁴⁹⁻⁵²

Parents As Teachers, another model that is being utilized in multiple sites throughout the state, serves parents from the prenatal period until age five, and includes the prevention of child maltreatment as one of its goals. While this program has demonstrated success in increasing parent knowledge and child school readiness, its impact on preventing child maltreatment remains unevaluated.⁵³

The Divisions of Public Health and Medical Assistance of the North Carolina Department of Health and Human Services sponsor two statewide case management programs that incorporate some home visiting. Baby Love, developed to improve birth outcomes, and the Child Service Coordination Program, developed to improve child health and development outcomes, serve Medicaid-eligible families in every county. Aside from infant mortality, specific outcome indicators have not been identified or monitored, so it is difficult to know which needs are being successfully addressed and how. But training is minimal, case loads are large, and contact hours with families are restricted to one hour and a half per month. Furthermore, community resources to which families can be referred are scant in many areas of the state. This is especially true for mental health and substance abuse services. Enhancements to the Baby Love and Child Service Coordination programs are being tested in some counties.

Parenting education and support programs. Parenting education programs, often directed at populations considered at risk for child abuse and neglect, generally aim to teach normal child development, positive strategies for parent-child interaction, including child discipline techniques and how to access community supports. These programs are offered to individual parents or groups of parents, in a variety of settings, including home visits, clinic visits, or in the community. Some parenting programs focus more on the provision of mutual support, especially as relates to parenting challenges. Evidence that group-based parent training programs can improve the psychosocial health of the mother, including reductions in depression,⁵⁴ suggests that these programs may provide effective social support while increasing knowledge and skills. Following is a list of well-known examples of parenting programs that have demonstrated some effectiveness in preventing child abuse and neglect.

- Parents As Teachers is an early childhood family support and parenting education program that is delivered through home visits beginning in the prenatal period and extending until the child reaches age five.
- The Nurturing Program, a parenting education and support program, targets families who have been reported for child maltreatment or who are considered at high risk. The

Nurturing Program tends to be offered more for parents who have already been reported to the Child Protective Service system.

The Triple-P or Positive Parenting Program was developed as a universal parenting program with multiple levels that provide increasing amounts of skill-development tailored to need. This program, which aims to prevent poor outcomes

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in children by enhancing the knowledge, skills, and confidence of parents, is currently being tested and evaluated at the University of South Carolina.

- Parents Anonymous is a parent mutual support program available weekly on a drop-in basis. The focus is to transform attitudes, learn behaviors, and create long-term positive changes in families.
- The Circle of Parents[®] Program is another mutual support program that is described elsewhere in this issue.⁵⁵

Parenting programs are proliferating across North Carolina, but are not yet universally available or normative for all parents. The North Carolina Parenting Education Network (NCPEN), an unfunded collaborative of parenting education organizations and agencies, is working to credential and build the field of parenting education in North Carolina.

Economic and workplace policies. Community-based services for all new and expectant parents are important aspects of child

maltreatment prevention. Yet, even when such services are available and affordable, they may still be underutilized by the families that most need them. Impoverished families that are at the highest risk of maltreatment²⁶⁻²⁹ struggle with unmet needs for adequate education, employment, income, housing, transportation, and healthcare. These day-to-day struggles to meet basic needs may make it difficult to prioritize participation in programs or to use proffered services even when they are free. Public responsibility for supporting families must also consider the relationship between economic resources, economic policies, and poor parenting, especially in the current context of welfare reform.²⁹ Welfare-to-work agendas may need to be adjusted to ensure that families are able to obtain the help and support they need, while also ensuring that the family is able to manage economically. Job readiness programs could also work to connect these families with each other to foster the creation of new and positive social networks.

Also important are workplace policies that support families by allowing sufficient parental leave following the birth of a baby to support bonding and optimal nurturing for the newborn, time off for healthcare visits and participation in parenting programs, flex time to accommodate family needs, and leave to attend to sick children and family emergencies. Support for families through workplace policies has been found to benefit families and employers, but never considered specifically in relation to preventing child maltreatment. Ironically, family-friendly workplace policies in North Carolina tend to be concentrated in higher-wage businesses or institutions, and not available to low-wage employees who need them most. With the vast majority of parents now employed outside the home, the workplace must be considered a crucial partner in changing norms related to child protection.

Discussion

States have an important role to play in preventing child maltreatment. Through systemic changes in the way normative services, such as prenatal care and well-child care, are delivered, expectations about the types of support and community involvement that parents need in caring for their children will gradually change. In North Carolina, we are making in-roads into these systems, especially for Medicaid patients. This is good news, because these patients are at highest risk, and Medicaid-reimbursed services address the socioeconomic disparities in the availability of resources. It is important, however, that these changes in service delivery become universal to decrease the stigma that can be attached to being screened and referred, and because a significant proportion of non-Medicaid patients will also require additional assistance with parenting or with psychosocial problems. Careful screening beginning in pregnancy and repeated periodically in well-child visits, followed by titrated services where the type and amount of service are tailored to the need, should be available for all expectant and new parents. Special populations of expectant and new parents who are known to be at higher risk (e.g, adolescents) will require more intense services.

Another societal norm-not addressed in this paper, but deserving of attention-is that interventions designed to improve pregnancy, birth, and child rearing outcomes should be directed only to pregnant women and mothers. From pregnancy onward, women are considered to be the primary caretakers of children and by default, the primary ones to blame for child maltreatment, despite evidence that fathers play important roles both as protectors and offenders.^{56,57} Public interest in fostering fathers' involvement is increasing because of the recognized benefits of fathers' contributions to their families.⁵⁸ Teenaged and young adult males may need extra help to assume the full fatherhood role, but many, if aided, will work hard to be successful parents. As we begin to change norms related to society's role in preparing and supporting young parents, we may need programs that are targeted to males or that are explicitly tailored for fathers as well as mothers.

State investments in prevention have been shown to result in savings in terms of avoiding lost earning potential and the medical, mental health, educational, welfare, and criminal justice costs associated with child maltreatment. In a study conducted by the Michigan Children's Trust Fund, costs of providing preventive services to all first-time parents were compared to costs expended for child abuse and neglect treatment, with the conclusion that "investments in prevention can be cost-effective if they result in even modest reductions in abuse events."59 Similarly, the state of Washington conducted an analysis of early intervention programs and found that some programs (e.g., Nurse-Family Partnership Home Visiting and Parents as Teachers) give taxpayers a good return on their dollar, while other programs fail to generate more benefits than costs. The authors caution that states should not only track program objectives and results, but assure quality control, through program monitoring and implementation fidelity to evidence-based models.⁶⁰

There is substantial commitment to the prevention of child maltreatment in North Carolina, as demonstrated by the number of public and private programs for expectant and new parents that are currently being implemented across the state. Guided by the North Carolina Institute of Medicine Task Force plan,⁶¹ we can move closer to a real state-wide comprehensive, coordinated approach that is based on scientific evidence about successful approaches to prevention. Normalizing the concept of family support may require public awareness efforts concerning the importance of parenting, especially during the early years, as well as changes in service delivery to accommodate the needs of all new parents. With state leadership, communities can again become invested in the welfare of their youngest residents through enhanced pre-natal care, well-child visits, and other available services that provide parents with the training, resources, and support they need to nurture their children and to prevent child maltreatment from ever occurring. NCMedJ

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Child Abuse Homicides: A Special Problem within North Carolina's Military Families

Marcia E. Herman-Giddens, PA, DrPH, and Thomas J. Vitaglione, MPH

The media have done a good job of reminding us of the sacrifices that military families are called on to make, especially during wartime. Few of us, however, really understand the full spectrum of factors and circumstances that military families experience at all times.

Most of the military are young people and are paid rather poorly. They are not only subject to foreign deployment, but also to frequent changes of location within our country. Military families are thus separated from their extended families, and often feel a sense of isolation. Though there are support services available through the Department of Defense, most military families (as is also the case with civilian families) are reluctant to seek assistance, both out of embarrassment and an unwillingness to let the military hierarchy know that they are experiencing troubles.

In the Issue Brief for this issue, Michelle Hughes et al. describe the following "family risk factors" for child maltreatment: lack of resources; social isolation; inadequate monitoring

by other family members; family disruption; and the young age of parents and their children.¹ Note that these risk factors match the general description of military families in the prior paragraph.

Indeed, these considerations were not in the scope of the North Carolina Child Fatality State Prevention Team when it conducted a 1998 study of child abuse homicide.² Findings from that study led to another study published by the North Carolina Child Advocacy Institute (NCCAI) in 2004.³ The surprising results of these combined studies, along with some recommendations and the status of their implementation, are the basis for this commentary.

Child Abuse Homicides among All North Carolina Families: 1985-2002

Child abuse homicides are a significant cause of preventable injury deaths among young children in North Carolina. From the Child Abuse Homicide Study, published in 1998,² we learned that 85% of all homicides of children less than 12 years of age are due to child abuse, not "stranger danger." Most are committed by males, either the biological father or another male caregiver. Combining these numbers with ongoing data from the North Carolina Child Fatality State Prevention Team, we know that a total of 439 North Carolina children were killed by their parents or caregivers from 1985 through 2002 an average of one every two weeks for the entire 18-year period.

"In Cumberland County, the child abuse homicide rate for children of military families was 5.0 per 100,000 children ages 0-10. For Onslow children of military families, the rate was 4.9 per 100,000. Tragically, these rates are more than twice the state rate."

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Child Abuse Homicides among North Carolina's Military Families: 1985-2000

Data analysis found that counties with the two largest military facilities had by far the highest rates of child abuse homicides. That finding led to the further analyses below. As far as we know, North Carolina is the only state to have accurate child abuse homicide figures as far back as 1985. Therefore, we cannot compare ourselves to other states, and we do not know if these findings are typical for the country as a whole or are unique to North Carolina. Even so, the findings point out areas for improvement that would benefit all states and military installations.

North Carolina's Military Installations

North Carolina has six military installations. Only four, Pope Air Force Base and Fort Bragg in Cumberland County and Camp Lejeune and New River Air Station in Onslow County, had numbers large enough to provide statistically sound results. Comparing counties with small numbers is unreliable, since the results could be due to chance fluctuations. Therefore, we only studied the four installations and the two counties in which they reside.

How We Did the Study

We looked at all cases of child abuse homicides in children birth through ten years of age from Medical Examiner records. We stopped at the year 2000, since it was the most recent with complete data at the time we conducted the study. A military case was one where one or both of the parents or other caregivers who killed the child were on active duty at the time of the homicide.

The Findings

In this 16-year time period:

- 378 North Carolina resident children 0-10 years of age were killed by caregivers.
- The overall state child abuse homicide rate per year was 2.2 per 100,000 children ages 0-10.
- 26 small counties had no child abuse homicides during the 16-year study period.
- The rates for the larger population counties (Wake, Mecklenburg, Guilford) ranged from 2.1 to 2.4 per 100,000 children ages 0-10.
- Cumberland and Onslow counties had rates twice as high as the state average: 4.6 and 4.3 per 100,000, respectively.
- In Cumberland County, the child abuse homicide rate for children of military families was 5.0 per 100,000 children ages 0-10. For Onslow children of military families, the rate was 4.9 per 100,000. Tragically, these rates are more than twice the state rate.

Recommendations and Progress in Their Implementation

Understanding the root causes of parental violence against children and how to prevent it is obviously a complex issue. And the special stresses faced by military families only add to the complexity. This is not to say that the problem of child maltreatment in military families is being ignored. In fact, we commend the Department of Defense for its Family Advocacy Program, through which many services ranging from prevention to recognition and treatment on military installations are offered. It is clear from the tragic data, however, that much more needs to be done.

In the NCCAI issue brief on this matter, *Reducing Collateral Damage on the Home Front*,³ there are a host of national, state, and local recommendations offered for consideration. Below is a synthesis of these recommendations, along with notes on progress.

- Military installations should strive for improved investigations of child fatalities, including standardized procedures for all responders and the sharing of information with the appropriate military and civilian agencies. The Department of Defense is currently implementing a standardized fatality review process. This will provide more accurate data and a better understanding of the underlying causes of child abuse homicide in military families, hopefully leading to improved interventions that will prevent future occurrences.
- Military installations should provide an array of prevention services—including primary, secondary, and tertiary components—designed to decrease the occurrence of child abuse homicide. A family violence approach should be employed to reduce both spousal and child abuse. As noted above, the Family Advocacy Program sponsored by the Department of Defense already offers a broad array of services. Department officials are currently reviewing the Program both to enhance its relevance and to enhance access to services by military families in need.
- Local Task Forces should be established in the counties with the highest child abuse homicide rates to develop strategies for better communication among military and civilian agencies to enhance opportunities both for prevention and for the handling of cases when they do occur. Task Forces have been established in Cumberland and Onslow counties under the leadership of each county's department of social services and with the broad participation of community agencies and the military installations. Both groups have been quite active, and both have decided to take a broad community-based approach to the problem (i.e., a study of the occurrence of child abuse homicide in all families, not just military families). The enhanced spirit of cooperation has the potential to successfully address the critical problems at hand.

A Final Hope and a Final Word

It is likely that additional fiscal resources will be necessary to implement the enhanced services aimed at reducing the occurrence of child abuse homicide in military families. The North Carolina General Assembly has recently created the opportunity to access such resources through passage of the Military Support Act of 2005. Through tax breaks available under this statute, as much as \$2 million may be available to North Carolina's military installations annually to "improve the quality of life for military families." We hope some of these resources will be targeted to the tragic problems addressed in this commentary. All of us involved with this issue recognize that being in the armed services injects unique stresses and difficult situations into the family lives of the men and women who courageously serve. We are grateful for their service to our country. We also recognize the many on-going prevention services, training initiatives, counseling systems, and other programs and services provided by the armed services to lessen violence within their families. Still, our findings indicate that we need to do more. Society can, and must, reduce the frequency and severity of family violence at-large and within military families. Helping our military men and women and their families is an important way to really "support our troops." **NCMedJ**

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Margaret lives in her own place with her own stuff. Tracie helps to make it possible.

"Margaret is 85 and sharp as a tack. But her health makes it tough to get around. Tracie wants to help out in her community, but she has a busy job. *Faith in Action* brought them together. It's people of different faiths who volunteer to shop, cook, drive, or just check in on some of the millions of Americans with long-term health needs.

If you're like me and have wondered how you can



make a difference, volunteer with Faith in Action. A neighbor's independence depends on you and me."

FAITH IN ACTION Della Reese. Entertainment Legend.
 Faith in Action Believer.



Strengthening Families: The Role of Community-Based and Grassroots Organizations

Henrietta J. Zalkind, JD, and Pat W. Allen, MS

Currently, hundreds of community-based and grassroots organizations (CBOs) provide a safety net of support to families and children across the state of North Carolina. The common mission of these organizations is to strengthen outcomes for children, families, and communities. The role they play in these efforts is both significant and complex. The following is an example of one North Carolina community-based organization that is typical of the work happening every day across this sector.

Background of the Down East Partnership for Children

Down East Partnership for Children (DEPC) is a nonprofit organization located in Rocky Mount, in North Carolina. Although physically located in Edgecombe county, DEPC serves both Edgecombe and Nash county. The area is a combination of small towns and communities, large rural areas, and a city, Rocky Mount (population, 55,893), which straddles the county line. The population (Nash county, 87,420 and Edgecombe county, 55,606) is racially diverse within each county and across county lines. Nash county is 61% white, 34% black, 3% Hispanic, and 2% other; and Edgecombe is 57% black, 39% white, 3% Hispanic, and 1% other. Economically, the area is a mix of upwardly mobile middle-class families and both rural and inner-city low-income families. In 2000, the median household income was \$37,147 in Nash county and \$30,983 in Edgecombe County, with 13.4% of Nash County and 19.6% of Edgecombe county residents living in poverty.

DEPC was created in 1993 by a group of local community leaders who were concerned about the child/family statistics in the two-county area, including high incidences of poverty, low birth-weight infants, teen pregnancy, and child abuse and neglect. These leaders recognized that strengthening the family service systems in both counties by creating a coordinated, collaborative system of services across county lines would be an integral part of improving these problems.

To accomplish this, DEPC works in collaboration with

community partners to create and implement innovative, collaborative, and family-friendly services for children and families and to create long-term change in the early care, education, and human service systems. The DEPC mission is to improve the quality of life for children and families in Edgecombe and Nash counties through advocating and supporting quality, life-long education and facilitating a trusted and coordinated system of community services.

Programs and Services of the Down East Partnership for Children

DEPC provides a wide range of direct services for children, families, and early care and education providers. Programs for children and families are designed to enhance the development of children and to strengthen families in a safe, friendly environment in which the families feel comfortable asking questions, admitting need, and seeking help. Service providers are trained to focus on families from a strength-based approach, involving them in planning for long-term outcomes and empowering them to create their own changes.

Programs for early care and education providers are designed to enhance educators' abilities to provide the highest quality of care and education for the children and families they serve. DEPC provides training to help early educators understand the importance of quality health, safety, and educational standards and how to meet those standards. DEPC strives to help them recognize and value their role as first responders in identifying families who may be in trouble and children who are at risk for abuse and neglect.

Programs for children and families include resource and referral services to help families locate early and school-age child care and increase their understanding of the importance of choosing *quality* care. A child care scholarship program helps low-income families pay for child care. The children must attend a four- or five-star rated facility to ensure they have access to highquality early care and education. Families who receive the child

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care scholarship also agree to participate annually in eight hours of family education or family involvement activities designed to enhance their parenting skills and encourage their involvement in their child's education.

DEPC also supports families in their parenting role. Services include support groups for grandparents raising grandchildren and families with special needs children. A crisis child care program is available to help reduce the stress of families experiencing a crisis, and one-on-one support is offered to interested families to help them identify, plan for, and accomplish specific outcomes based on their family's needs.

Additional family services include a parent information library of videos, books, and other materials that families can check out at no charge; family education workshops and classes, and toddler and preschool playgroups. Finally, a variety of *Family Night Out* and *Family Fun Day* events are provided on a regular basis to reach out to families, build trust, and engage them in more active learning about parenting.

Programs for early care and education providers include training and technical assistance to help them develop and

"Programs for children and families are designed to enhance the development of children and to strengthen families in a safe, friendly environment in which the families feel comfortable asking questions, admitting need, and seeking help."

maintain quality care and education programs. DEPC also works to professonalize the early care and education system by working to ensure that all providers have wages equal to the important role they play.

In order to meet the needs of all families throughout the two-county area, DEPC also acts as a financial intermediary, funding 29 programs in ten partner agencies. For example, DEPC funds:

family support programs through community-based family resource centers to eliminate typical barriers that families face when seeking services, such as lack of transportation and fear and distrust of governmental institutions outside their own neighborhoods;

- a two-county community health program that provides health and safety education and works to ensure that all children have up-to-date immunizations and a medical home;
- kindergarten transition programs in both Nash-Rocky Mount and Edgecombe County Public Schools designed to ensure that all children enter school healthy and ready to succeed;
- a salary supplement initiative for child care providers in the two-county area based on longevity and educational level. The supplement initiative is designed to increase provider education and decrease turnover, both of which affect the quality of care and education that a center can provide.
- additional staff for the Nash and Edgecombe counties' departments of social services to enhance their abilities to manage their child care subsidy program, which helps ensure that all families have access to child care when needed.
- the management of *More at Four*, North Carolina's initiative to make quality preschool education available for at-risk four-year-old children.

All DEPC programs are managed through a performancebased contracting, monitoring, and evaluation process that has been in effect since 1994. All programs must support the DEPC mission and be working toward one or more of the following goals: (1) Universal Access to Quality Education; (2) Improved Parenting and Parent Involvement in Education; (3) Elimination of Barriers to Services and (4) Improved Transition to School. Annual outcomes are negotiated for each activity and program and must support clear progress toward five-year community-wide indicators/benchmarks of child/family well-being. For complete program and evaluation information, please see the DEPC web site at: www.depc.org.

Strengths

While DEPC is one of the hundreds of nonprofit CBOs in North Carolina working to improve the quality of life of children and families, all CBOs share a similar set of strengths that many government or for-profit organizations lack. For example, CBOs have the ability to create trust, are multi-sectoral, are mission driven, are able to meet family needs quickly, have limited bureaucracy, are not surrounded by a "government stigma," and have local support.

Because CBOs are community-focused, they are able to create an environment where parents and children feel nurtured. Having this environment helps develop trust and allows learning to occur. Over a period of time this creates a culture of success in both the families and ultimately in the community they live in. In addition, working with a CBO does not involve the stigma of seeking help from the government. Working without this stigma helps normalize and encourage all families to improve their support systems and information base.

Most CBOs operate more entrepreneurally than government

agencies and thus, can be more innovative and adaptive to their communites' needs. Because they may also have limited bureaucracy, they can model the pro-active behavior that families and children need to be successful.

Meeting community needs is also enhanced by the CBO's ability to work across agencies, organizations, and disciplines to create holistic supports and solutions for families and children. Since CBOs are mission-driven, rather than profit or insurance driven, the services are almost always free, which eliminates the financial barrier that families often face when seeking help.

CBOs also share a strength in being able to act as both a triage and a feeder system. Acting as a triage system, CBOs help divert families from needing more intensive and expensive services (e.g., foster care, special education). Acting as a feeder system, CBOs help connect families in need with appropriate services when such services are needed.

Finally, CBOs have the support of the local community, in terms of volunteers, funding, and political influence. This support is critical to the change process not only in individuals and families, but also in the community.

Challenges

Being a CBO also has its share of challenges. During this recent period of record budget shortfalls, CBOs have faced increasingly difficult financial challenges. For example, many CBOs lack stable funding that is unrestricted and financial support for infrastructure and resource development. Some CBOs find it difficult to stay on mission and maintain a local agenda, as they are forced to follow funding or face closing. Funding issues also make it difficult for CBOs to hire and retain staff who have the skill level necessary to both implement evidencebased programs and operate in an environment of continuing change. Qualified staff are competitively sought after and can make significantly more money outside of the nonprofit sector.

The demand for immediate results presents another challenge for CBOs. Changing family systems and documenting child and family outcomes is both time and money intensive. Funders can be impatient with the change process and reluctant to commit long-term resources to the services and evaluation needed to produce evidence of long-term program success. Along with the challenges, is the ever-increasing demand for

accountability. While certainly understandable from a publictrust standpoint, most CBOs have multiple funders with varying reporting requirements and timelines. The time and energy required to satisfy multiple funders can be staggering.

Conclusion

While the work of community-based and grassroots organizations may not fit easily into a scientific, evidence-based model, it undeniably creates a system of support missing in today's transient society. Providing support that previously came from extended families living in closer-knit communities, CBOs connect people to each other and to the help that we all need to be successful parents. These family services play an essential role in decreasing risk factor for abuse, improving outcomes for children, and helping families and communities create long-term change. Perhaps consumer voices explain the benefits that this sector contributes best. Below are comments from some of the clients and staff involved with the DEPC programs.

"I really enjoyed the group because it gave me a chance to hear others talk about their household and changes that I can make." (Playgroup participant)

"I learned how to be a better advocate at school meetings." (Effective parenting workshop participant)

"I learned how to control my anger and not take my frustrations out on my daughter...We are communicating better and our relationship is improving." (Parent Information Center user)

"I often discuss tips for kindergarten success with parents. One parent told me what a difference I had made in her life. I asked her 'Don't you mean in your child's life?' She said, 'No, my life. Your kind words of encouragement really help me display that same attitude in my parenting.' To reach a child, I must first reach a parent. (Early Childhood Contact)

"DEPC gave me confidence that I can help solve community and family problems." (Community Fellow Graduate) **NCMedJ**

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The Circle of Parents[®] Program: Increasing Social Support for Parents and Caregivers

Katrina D. Gay, BSPH, MPH

eaching out for help is often difficult in our society, where independence and self-sufficiency are highly valued, and asking for help is often associated with feelings of shame and perceptions of being weak. Our rugged individualism has led to a rejection of the "village approach" to raising children. These days, parenting assistance from neighbors and other community members is more likely to be viewed as intrusive and meddlesome. Research shows that families across the nation are experiencing increasing stress, but most are not seeking help. A 2002 survey of parents conducted by the YMCA and Search Institute found 78% of parents feel that talking with other parents about parenting issues would help "very much" or "somewhat." They also reported as helpful: receiving affirmation of their parenting skills and practices, seeking advice from professionals they trust, and having other adults they trust spend time with their children. However, 53% of parents surveyed said that they do not regularly reach out for parenting help from any of these sources.¹ This hesitancy to ask for support, coupled

with societal norms of family privacy, creates a culture in which parents often struggle to raise their children without the assistance of a supportive social network.

Social support for families is a critical issue when looking at familial risk factors for child maltreatment. Particularly when a lack sitancy to ask for support, coupled and support for parents by parents, providing lasting friendships *…there is great potential for supporting* parents in communities. Yet, most parents may not be looking for formal programs or workshops, but may be interested in informal, relational opportunities for learning, affirmation, and support."

outcomes.5

of social support is paired with other challenges (e.g., poverty, interpersonal conflict, substance abuse, and mental health issues) parenting effectively becomes increasingly difficult. In *Social Support and the Prevention of Child Maltreatment*, RA Thompson defines social support as, "social relationships that provide (or can potentially provide) material and interpersonal

for participants. The program structure consists of a trained professional facilitator who co-leads weekly group meetings with a parent leader (or multiple parent leaders). Participants are provided with a safe, nonjudgmental environment for peer support and guidance from other parents who share common experiences, successes, and challenges. An accompanying children's

resources that are of value to the recipient, such as counseling,

access to information and services, sharing of tasks and responsibilities, and skill acquisition."² Reviews of research consistently

show that parents with a social network of friends, family, and

community members are able to parent more effectively. On the other hand, maltreating families are consistently characterized

by a lack of connection to healthy support networks that could

provide emotional nourishment, guidance, access to resources, behavior monitoring, and opportunities for learning, growth,

and reciprocity.^{1,2,3,4} Despite the importance of social support to

healthy family functioning, most child abuse prevention strategies

have not fully incorporated strategies to increase this protective

factor. This is a missed opportunity, as programs that offer parents

the opportunity to connect with other parents to give and

receive emotional and practical support have evidence of better

The Circle of Parents® program provides a source of strength

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program that mirrors the parents' group is provided if resources allow, or quality childcare customarily is provided at no cost.

Social support can impact a family on many different levels contributing to the prevention of child maltreatment. Thompson lists several functions of social support strategies to prevent child maltreatment that the Circle of Parents[®] program fulfills, including: emotional sustenance; counseling, advice, or guidance; access to information, services, and material resources and assistance; skills acquisition; and social monitoring and social control.²

Each one of these functions is described below, along with explanations of how these functions present themselves in Circle of Parents[®] groups.

- Emotional sustenance. Emotional sustenance encompasses feelings of empathy, connectedness with others who share similar life circumstances, and enhanced self-confidence. The Circle of Parents[®] program provides a forum for emotional sustenance by allowing participants to build relationships and connect with other parents with whom they share something in common. Participants gain a sense of belonging and relief as they learn that their family dynamics and their child's behavior are often more typical than exceptional. They also are provided the opportunity to give and receive help, which lessens feelings of indebtedness.
- Counseling, advice, or guidance. The counseling, advice, and guidance that is provided through the Circle of Parents[®] program is primarily provided by the other parents in the group and is often better received than if it had been provided by a professional. Participants are assured of an accepting, nonjudgmental environment where their conversations will be kept confidential (within the limits of the law). They become resources to each other inside and outside of the group by sharing coping strategies and parenting skills from parents who have "been there." The presence of the professional facilitator helps assure that what is shared encourages positive parenting strategies.
- Access to information, services, material resources, and assistance. The level of information sharing that occurs in groups can be much more meaningful than that traditionally provided through professional support systems. Parents are able to provide and obtain real-life examples of coping strategies and parenting techniques that have been tried, and they are able to learn whether they succeeded or failed. When sharing information about community resources and services, parents can convey their own experiences with them, reveal names of individuals who they have found to be particularly helpful, and communicate how best to navigate the various human service systems in the community.
- Skills acquisition. Not only are parents provided with information about new parenting skills in these group settings, but they are also provided with the opportunity to "practice" them in the safe, supportive environment that the group provides, helping them to integrate these new parenting skills into everyday life. Group members use problem-solving techniques, communication skills, and conflict resolution within the

group and are able to refine these skills for effective use at home. Parents also have the opportunity to report on their own experiences of implementing parenting skills at home and get feedback from the group.

Social monitoring and social control. Possibly the most important function of social support, as stated by Thompson, that the Circle of Parents® also provides is social monitoring and social control. Participants in the groups develop a sense of community with their own group norms and values. Groups are even encouraged to develop group rules that reflect these norms and values and often include things, such as nonviolence and personal accountability. These agreed upon rules allow for group members to monitor behavior and point out behaviors that don't conform to the rules with less fear of anger and rejection.

Mutual self-help parent support-group programs, such as the Circle of Parents®, are uniquely able to provide emotional support, while at the same time challenging parental perceptions and behaviors through peer pressure, role modeling, and compliance with group norms. Parents have many opportunities to "give back" the help they have received, but there is no demand that they do so. In addition, self-disclosure and helpful advice may occur more easily because of the lack of personal intimacy among group members. Group members are not really a part of a parent's ongoing social network, and therefore, the risks of disapproval and criticism are lower, which contributes to conversation that is more candid.^{2,3} Sometimes, informal social networks, such as family and friends, may reinforce poor parenting behaviors, intrude on personal privacy, be resentful if support cannot be reciprocated, and even be a source of stress. On the other hand, formal support agents (e.g., counselors, social workers, healthcare providers) must maintain professional boundaries, and therefore are limited in their ability to fill families' needs for emotional nurturance. Typically, families are also discouraged from reciprocating help from formal support agents, which contribute to feelings of indebtedness.

It is important to note that there are often reasons why at-risk families are socially isolated. They can sometimes be very needy and demanding of their social networks, and therefore extremely draining for those trying to provide support. They may have poor communication skills or simply do not know how to have healthy, respectful, reciprocal relationships because they haven't seen or experienced them. These families can often benefit from safe, nonjudgmental opportunities to learn how to have healthy relationships. The Circle of Parents[®] program allows families to learn by example, modeling, and "testing" relationship skills in a supportive forum, while building new relationships. They offer safe venues within which to admit mistakes, make mistakes, and to learn new strategies for avoiding those mistakes in the future.

The United States Office of Juvenile Justice and Delinquency Prevention recognizes and supports mutual self-help support groups for parents as an effective program strategy.⁶ In addition, this intervention strategy is well received by the parents who are involved, further contributing to its success. Parents who participate in parent mutual self-help support groups consistently voice satisfaction with the program and report that it is beneficial.^{3,7,8}

While the Circle of Parents® program has a strong theoretical foundation, evaluation has been limited to nonexperimental studies. The available research clearly indicates that the Circle of Parents® model is a promising strategy for strengthening families and preventing child maltreatment. These studies indicate highly positive results for families by addressing risk factors for child maltreatment while enhancing family strengths. Results include the following components that have been shown to contribute to effective parenting and healthy family functioning:

- Parents increase their social support network by connecting with other parents and community resources.^{7,8,9}
- Parents have more confidence in themselves and their parenting abilities.^{7,8,9}
- Parents learn new parenting skills and becoming familiar with child development. ^{5,7,8,9}
- Parents learn and demonstrate problem-solving skills.⁵
- Parents learn new ways to cope with stress and manage impulsive reactions.^{5,7,8,9}
- Parents become empowered to influence other parents and their community.⁷

Not only are there positive outcomes for families, but implementing the Circle of Parents[®] program is relatively inexpensive. With limited dollars available, existing programs struggle to serve the most vulnerable families in our communities. This low-cost, common-sense approach capitalizes on available resources, including a community's "natural helpers," particularly other parents. It is an ongoing, consistent source of support that families can count on, even when they have "aged-out" or been determined ineligible for other services. The Circle of Parents[®] program works to reduce child maltreatment by filling a gap in services and providing social support to families during these times of extremely limited resources and poor connections between parents.

The Search Institute's research found that 97% of parents feel there is more they can learn about being a good parent. The researchers concluded, "there is great potential for supporting parents in communities. Yet, most parents may not be looking for formal programs or workshops, but may be interested in informal, relational opportunities for learning, affirmation, and support."¹ The Circle of Parents[®] program can provide that more informal source of support.

Prevent Child Abuse North Carolina sponsors the Circle of Parents[®] Network in North Carolina, with the generous support of The Duke Endowment, providing centralized support, resources, training, and technical assistance to local programs participating in the Network, to promote best practices in providing services according to the Circle of Parents® model. It is envisioned that these programs will eventually be available statewide, preventing child maltreatment and strengthening North Carolina families. A statewide advisory committee, which includes state agency representatives, local program staff, and parent leaders, guides our work while building and maintaining the network. Assistance is available to help identify and secure funding for Circle of Parents[®] programs at the local, state, and national levels. A portion of the funds from The Duke Endowment is also made available through a Request for Proposal process to local Circle of Parents® sites that form supportive partnerships with the faith community. If you are interested in starting a Circle of Parents® group in your community, please contact Katrina Gay, Program Coordinator, North Carolina Circle of Parents® Network, at 1-800-CHILDREN or email kgay@preventchildabusenc.org. For more information on the Circle of Parents® national model, please visit www.circleofparents.org. NCMedJ

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The Role of Philanthropy in Child Maltreatment Prevention Efforts

Rhett N. Mabry

The Duke Endowment has long been interested in the welfare of children. In his Indenture of Trust that established The Endowment in 1924, James B. Duke expressed a desire to help children who had been orphaned from their families. Today, we recognize that children are less likely to be

orphaned in the traditional sense of the word (by the death of their parents). They are more likely to be "orphaned" by the actions of their parents—namely, child abuse and neglect that results in the state (through county departments of social services) taking custody of the child.

This recognition has led to dramatic changes in the way The Endowment supports child welfare.

Today, The Endowment places great emphasis on funding prevention and early intervention efforts to stem the flow of children who enter foster care and to keep children safe in their homes and communities.

The Role of Philanthropy

From the time our national child welfare system was created, funds have been directed toward responding to identified cases of child maltreatment. And for many years, we believed the number of maltreatment cases was small. Not until Henry Kempe published *The Battered Child Syndrome* in 1962 did people come to realize that parents were mistreating their children.¹ As recently as 30 years ago, law enforcement and social service agencies nationwide fielded 60,000 reports of suspected child abuse and neglect per year.² Today, that number is nearly three million.

Given the weight of these numbers, the current system is outdated and woefully inadequate. County departments of social services (DSS) do not have budgets that can handle current case load levels, and only limited public funds actually target preventive or early intervention efforts that might slow the stream of children entering foster care.

Foundation funding can help address this shortfall by providing funding for prevention. Effective prevention efforts could not only help children and families, but could ease the

"Today, we recognize that children are less likely to be orphaned in the traditional sense of the word... They are more likely to be 'orphaned' by the actions of their parents..."

> cost burden to the state and counties by reducing the case loads and the other costs associated with child abuse (i.e., mental health, special education, justice system). But to effectively reduce child abuse, foundations must be willing to fund carefully planned, well-documented pilot efforts. Ideally, such pilots will be able to demonstrate the logic of preventing child maltreatment in addition to stimulating changes that might lead to a more effective system for supporting families and children. Successful demonstrations could also help convince legislators and policy makers that the old adage of "an once of prevention is worth a pound of cure continues to hold true."

Comprehensive Strategies

Reducing the risk factors of child abuse and neglect (e.g., poverty, substance abuse, single parent homes, domestic violence, parental stress, mental illness, etc.) will require a comprehensive, coordinated strategy aimed at the entire community. Too often, funders, including The Duke Endowment, have supported fragmented programmatic efforts for segments of the populations rather than community-wide programs. By design, these efforts

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are limited in scope and invite unnecessary service duplication across multiple agencies.

Like Child Protective Services, programmatic efforts funded by foundations are often reactionary and fail to address the systemic factors that lead to child maltreatment. While necessary—and in some cases effective in supporting individual families where maltreatment is suspected—such an approach is arguably inefficient and, in the aggregate, cost-prohibitive. Instead of continuing to fund such limited programs, foundations should fund programs with evidence supporting their ability to create systemic change.

Another challenge programs face in providing interventions that will prevent child abuse is the families' perception of the stigma attached to receiving such support. Offering services universally (to everyone in a community) is a research-based strategy promoted to reduce the stigma that is often associated with receiving family support services. For example, if all expectant families receive parenting education, the social norm is more likely to change. Instead of potentially being seen as a program for the less capable, the community will come to expect this education. Helping the entire community become more accepting of family support services is not only important in terms of reducing the stigma low-income families may feel, but it also helps to engage the entire community. While poverty is a risk factor, abuse and neglect occur across all socio-economic groups. Universal programs will also help extended family and neighbors "re-discover" their role as a support network for young families.

Guiding Principles for Effective Funding of Child Abuse Prevention

In addition to providing a comprehensive approach that includes community and family involvement, foundations should consider several other key principles.

Listen to providers. Service providers are on the front lines finding ways to best serve children. Foundations are several steps removed. Foundations should strike an interactive posture with grantees, as opposed to a prescriptive or authoritarian approach. Grantees, in turn, should recognize that the knowledge they hold is just as important as the money foundations offer.

Support evidence-based interventions. Many service providers offer intervention programs that lack any evidence of effectiveness. For instance, child self-protection classes ("Good Touch/Bad Touch") are commonly used as a line of defense against sexual predators. In reality, such training has proven far more effective in disclosing past inappropriate behavior than in preventing future assaults.³ According to the findings of the North Carolina Institute of Medicine Task Force on Child Abuse Prevention, strong evidence supports the effectiveness of only a few programs. These include the Nurse Family Partnership (Olds model), Parent Child Interaction Therapy, the Strengthening Families Program, and the Chicago Child Parent Centers.⁴

Insist on clear and understandable measurement. It is imperative that projects have appropriate outcomes measurement. Appropriate means several things, including:

- Being realistic about the scale and scope of the effort. Chances that a one-year, \$25,000 grant will reduce child abuse in a given community are remote. Design outcome objectives that are appropriately matched with the resources being implemented.
- Identifying measures that are understandable to lay audiences. Pre- and post-test clinical scores regarding behavior improvement are fine, but be sure to track indicators the average parent or policymaker will understand. These indicators could include preparing for school readiness, increasing parental employment, accessing quality child care, securing medical homes, reducing family isolation, and enhancing community involvement, etc.
- Balancing qualitative with quantitative measures. Be prepared to share the anecdotes as well as the hard statistics; both tell important stories.

Provide long-term funding. The typical model for foundation grant support entails three-year obligations in declining annual amounts. Foundations have assumed that a funding period of three years provides ample time to test an approach, document its effectiveness, and attract sustaining resources, while weaning off grant support. For many projects, this model is effective and appropriate. For large-scale comprehensive, community-based approaches to preventing child maltreatment, however, the three-year funding model is inadequate. The complexity of child abuse and neglect demands longer grant periods. Changes in human behavior are gradual, not immediate. The same can be said for changing the culture and values of communities. A longer window will allow for more valid assessment of measurable change at the community level.

Pulling It All Together: The Duke Endowment's Child Abuse Initiative

Embracing the aforementioned tenets, in 2002 The Duke Endowment launched a planned ten-year effort to reduce child abuse and neglect by measurable amounts. Begun in Durham, North Carolina and Greenville, South Carolina, with programs led by researchers from Duke University and Clemson University, the initiative is the Endowment's most comprehensive effort to document the results of programs for preventing child abuse and neglect.

The primary goal of this initiative is a reduction in child abuse rates within the targeted service areas. To achieve this goal, each site is implementing strategies focused on the following objectives: improving parenting practices and behaviors, strengthening the community's formal service systems, and improving the capacity of community residents to protect children and support parents.

Each community has implemented approaches to address key risk factors for child maltreatment. In Durham, the Durham Family Initiative, under the direction of Dr. Ken Dodge, is focusing primarily on risk factors for parents and families and secondarily on the broader community and culture. In Greenville, the Strong Communities program, under the direction of Dr. Gary Melton, is focusing primarily on cultural risk factors and secondarily on individual families.

The evaluation plan, under the direction of Dr. Deborah Daro of Chapin Hall at the University of Chicago, is also welldefined, including door-to-door surveys in the service areas and comparison communities to capture information on community norms, neighborhood perceptions, available social supports, organizational involvement, and parenting behaviors and practices. The surveys are scheduled every three years to assess the effectiveness of interventions and to mark progress toward goals. Also, the grantees themselves (Duke and Clemson) will conduct site-specific evaluation studies examining public data, available services, volunteerism, effectiveness and coordination of specific programs, and participant observations.

Conclusion

Child abuse and neglect is a serious societal ill that produces many negative consequences. Evidence suggests that victims of child abuse and neglect may demonstrate attention deficit disorder

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and lower IQs. Behaviorally, common by-products of abuse and neglect include substance abuse, depression, anxiety, and excessive stress. Developmentally, speech, language, and gross motor delays may result, which is understandable, given that victims will have difficulties developing trust, social relationships, and attachments. Finally, and perhaps most tragically, almost a third of abuse and neglect victims will go on to abuse their own children.⁴

Foundations that desire to foster advances in society could not pick a more significant issue as a lever for change than preventing child abuse and neglect. As Abraham Lincoln once said,

A child is a person who is going to carry on what you have started. He is going to sit where you are sitting, and when you are gone, attend to those things which you think are important. You may adopt all the policies you please, but how they are carried out depends on him. He will assume control of your cities, states, and nations. He is going to move in and take over your churches, schools, universities, and corporations ... the fate of humanity is in his hands.² **NCMedJ**

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The Benefits of a North Carolina Policy for Determining Inappropriate or Futile Medical Care

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Editorial Note: Readers of the Journal will recall that in the July/August issue of 2004 (Volume 65, Number 4), we chose the topical theme of "New Directions in End-of-Life and Palliative Care." Reaction to this issue has been very positive, but a number of additional issues have been raised in North Carolina and around the country, which are worthy of our consideration. The commentary that follows summarizes an effort by some of the leadership in our state's medical profession to address one of these matters and is presented here as a policy change proposal for further discussion and debate.

ntractable conflicts sometimes develop among patients or L their surrogates and clinicians where protracted negotiations and discussions fail to result in a course of action tolerable to everyone. In 1999, Texas passed the first legislation to deal with such disputes. The legislation tries to honor patients' or their surrogates' rights and values, but is also based upon a notion of professional integrity, respecting the fact that physicians are the most skilled in determining appropriateness and inappropriateness in medical care. Individual physicians or institutions do not have immunity from civil or criminal liability in making decisions against the patients' or surrogates' wishes unless they go through multi-stepped procedures involving a medical staff or ethics committee. Patients or their surrogates may avoid or abort this process by seeking other caregivers or turning to the courts. This due process policy has proved successful in helping to solve entrenched disputes among clinicians,

patients, and families. North Carolina should adopt a policy using this portion of the Texas law as a model.

The Problem

Conflicts sometimes develop among patients or their surrogates and clinicians about the appropriate medical course to follow. Many conflicts are resolved with patience, better communication, and education. Nurses, social workers, patient representatives, chaplains, and other representatives along with physicians can help clarify options and prognoses in a way that fosters general agreement about what courses of action are acceptable for the patient. There are times, however, when protracted negotiations and discussions end in irreconcilable differences, and no course of action seems tolerable to everyone. At times these disagreements may reflect deep-seated views about the meaning of life or duties to vulnerable people. In what follows, we focus on the subset of these intractable disputes where requests by families or patients are judged to be inappropriate by all, or almost all, clinicians.

Three Options for Resolving Conflict over Courses of Treatment

In these rare cases where irreconcilable differences remain, and no courses of action seem acceptable to everyone, clinicians

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are left with three choices. First, they can acquiesce to the patient's or their surrogate's continued demands, such as to sustain life when all or almost all clinicians believe such support is not medically appropriate as judged by current practice standards. This response, however, tramples the clinician's own ethical and value judgments and undercuts the integrity of professional medical practice standards. Many clinicians have been critical of this stance, arguing it unreasonably defers to patients or families.^{1,2}

Second, clinicians may choose to respond by returning to a form of medical paternalism, imposing their clinical judgment on patients and families. These challenging situations arise in the context of medical treatment, and as such, estimates about treatment that is futile, useless, unsafe, or inappropriate should be understood in the context of medical science. These circumstances make practice guidelines particularly important in assessing reasonable expectations, probable effects of treatments, and why clinicians, as a group using these guidelines, are the best judge of what medical care is appropriate. Nonetheless, this recommended return to unilateral decision-making by physicians tramples patients' and families' choice and has been repeatedly rejected by policy makers and the courts, so for a great variety of reasons, this option seems unlikely to prevail.

Third, in response to sustained disagreements, Texas has turned to procedural justice, developing a due process method to solve intractable conflicts concerning what care is medically inappropriate. This solution has many advantages. It avoids the pitfalls of both medical paternalism and of ignoring practice guidelines. In addition, it ensures that the views of families or patients are not crushed by those in authority. In our view, a policy for North Carolina based on the Texas law offers the best way to deal with this type of entrenched legal or moral dispute.³

Due Process as a Way to Resolve Disputes

The publication of the report, "Medical Futility and End-of-Life Care," by the American Medical Association's (AMA) Council on Ethical and Judicial Affairs in March 1999 was an important step toward resolution of such disagreements by a due-process method.⁴ The report recommends using an open and fair process for considering futility cases with joint decision-making by the physician and the patient or surrogate, use of consultants and ethics committees, and attempts to transfer patients to other physicians within the institution or at another institution if the conflict between the patient or surrogate and physician about how to proceed cannot be resolved. In an unresolved conflict, the Council proposes, "if transfer is not possible because no physician and no institution can be found to follow the patient's and/or proxy's wishes, it may be because the request is considered offensive to medical ethics and professional standards in the eyes of the majority of the healthcare profession. In such a case, by ethics standards, the intervention in question need not be provided, although the legal ramifications of this course of action are uncertain."⁴ It further recommends that "health care institutions, whether large or small, adopt a policy on medical futility, and that polices on medical futility use a fair process approach such as that presented above."4

The AMA's Council on Ethical and Judicial Affairs recognizes

that irreconcilable conflicts about how to proceed with end-oflife care are sufficiently frequent that their resolution should be addressed. Further, the AMA proposes that clinicians, patients, and patient surrogates should resolve their conflicts with an open and fair process mechanism. The last step in the AMA's due process mechanism, which states that it is ethical to unilaterally cease futile interventions, is problematic because the legal implications are unclear. Uncertainty about the legal implications of acting against the patient's or surrogate's wishes often prevents physicians from taking that step, despite agreement among all or almost all clinicians.

The Texas Advance Directive Act of 1999³

Near the time of the AMA Council's report, a group of hospitals in Houston, Texas, working together through a joint ethics committee, formulated a "multi-institution collaborative policy on medical futility,"5 which subsequently became the basis for state-wide Texas legislation.⁶ The cooperation of individuals from a broad spectrum of political views led to the creation and successful application of this legislation, which now provides a legislatively-sanctioned, nonjudicial, fair-process mechanism for resolving end-of-life conflicts.³ The legislation offers a mechanism to discontinue medically inappropriate care after appropriate efforts have been made to resolve the ethical conflict existing between the treating physician and the patient or surrogate. Contrasting with the AMA Council's recommendation to withhold certain medical treatment based on *medical futility*, Texas law bases this recommendation on medical inappropriateness. The legislation is based upon a notion of professional integrity and respects the fact that physicians are the most skilled in determining medical appropriateness and inappropriateness. However, it does not allow an individual physician to have a legal safe harbor in deciding to withhold or withdraw treatment against the patient's or surrogate's wishes without going through a hospital committee-either a medical staff committee or an ethics committee. Typically, these committees have chaplains, medical ethicists, community representatives, and administrators, as well as doctors and nurses. Committees may find they agree with the patient or surrogate and not the attending physician. In any case, the patient or surrogate can turn to the courts if they lack confidence in the process or the impartiality of the committee. The law further recognizes that clinicians sometime disagree and encourages transfers of patients to physicians who share the values of the patients or their proxies.

The law³ developed in Texas and signed by then Governor George W. Bush in 1999, offers a procedure for granting immunity from civil or criminal liability for attending physicians and institutions who wish to refuse to honor patients' requests, advance directives, or surrogates' requests made on behalf of patients. The law stipulates that first, such decisions must be reviewed by an ethics or medical committee to which the attending physician does not belong, and second, the patients "...shall be given life sustaining treatment during the review." (This and the following quotes are from §166.046.)⁶ In what follows, we offer a brief summary of the steps that must be taken:

- (1) The patient or surrogate "shall be informed of the committee review process not less than 48 hours before the meeting..." and must be given information about the process and hospital policy.
- (2) The patient or surrogate must be invited to participate in the meeting and given a "copy of the registry list of healthcare providers and referral groups" that may be willing to take over their care or that of their relative.
- (3) The physician and the patient or surrogate must receive a written explanation of the committee's decision.
- (4) If the ethics or medical committee agrees that the care requested by the patient or surrogate is inappropriate, they should work together to find another physician or institution willing to provide the care sought by the patient or surrogate.
- (5) If after 10 days from the time of the committee's decision and notification of the patient or surrogate, the committee does not find an institution or clinician willing to care for the patient, the institution and attending physician are no longer obligated to provide therapy that has been determined to be medically inappropriate.
- (6) A court may extend this time beyond 10 days if a preponderance of evidence shows that another physician or institution may soon be found to consider accepting transfer.
- (7) Where no extension is sought by the patient or surrogate and none granted by the courts, clinicians and institutions are permitted to withhold or withdraw treatments they judge to be inappropriate, and they are immune from civil and criminal prosecution.

Does It Work?

The Texas legislation was the first of its kind in the United States and appears to be successful.⁷ First, it acknowledges the values and interests of both clinicians and patients or their surrogates. For the patient or surrogate, the legislation does not permit a paternalistic or unilateral decision to withdraw therapy by a single physician or institution against the patient's or surrogate's wishes. Such support can only be withdrawn if it is morally troublesome, not only to the physician, but to members of the review committee. Furthermore, the treatment can only be withdrawn or withheld if no other physician can be found (including at another hospital) who is willing to provide the support the patient or surrogate desires. Thus, a very high

community standard of inappropriate care is used in an open process that determines medically inappropriate care. Second, the legislation, through the open process it provides, makes it legal for physicians to discontinue treatment and have assurance that they are not making a decision that will be questioned by their colleagues or other healthcare peers. The legislation also provides a legal safe harbor for the physicians and institutions in that both are provided immunity from civil or criminal liability if they follow the process provided.

A recent report from MD Anderson Hospital in Texas shows the benefits of the Texas legislation. After the Texas legislation passed, the number of referrals to the hospital ethics committee to evaluate end-of-life care decisions increased significantly because the physicians believed that making such referrals was no longer a futile exercise. Also, in that hospital, a number of cases were taken through the review process and care was unilaterally discontinued when the review committee concurred with the physician that continuing or providing certain care was not appropriate. Although not all patients or their surrogates were pleased with the process, many of them did feel relieved and accepted the committee's recommendations once the decision to discontinue life support was taken off their shoulders.⁷ The physicians were also relieved that they were no longer required to provide care that they believed violated their ethical principle to "do no harm" and that was also against their medical judgment and the professional standards of care. It is also possible the review committee may support the views of the patient or surrogate, but arguably there are benefits to the patient or surrogate even if they do not. They have a full airing of their concerns and are provided written responses from the review committee. In addition, they have the opportunity to find other clinicians or institutions that would support their views. They can also turn to the courts at any time if they believe the process is unfair or the committee is not impartial. Finally, there is a benefit of avoiding unsafe and medically inappropriate interventions.

We believe a consensus might exist among clinicians, state representatives in the legislature, and citizens of North Carolina to implement a law similar to that passed in Texas. This law would address the relatively rare, but extremely troubling demands by patients or their surrogates for care, which all, or almost all clinicians, regard to be inappropriate given patients' medical conditions. **NCMedj**

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North Carolina Institute of Medicine



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he purpose of the North Carolina Child Health Report Card is to heighten awareness—among policy makers, practitioners, the media, and the general public—of the health of children and youth across our state. All of the leading child health indicators are summarized in this one, easy-to-read publication. This is the eleventh annual Report Card, and we hope it once again will encourage everyone concerned about young North Carolinians to see the big picture, and then rededicate themselves to improving the health and safety of the children whose lives they affect.

Statewide data are presented for the most current year available (usually 2004) with a comparative year (usually 1999) as a benchmark. Unless otherwise noted, data are presented for calendar years. The specific indicators were chosen not only because they are important, but also because there are data available. In time, we hope expanded data systems will begin to produce accurate data that would allow the "picture" of child health and safety to expand as well. For several indicators, county data can be accessed through the web site of the NC Child Advocacy Institute (www.ncchild.org).

The data provide reason for celebration and concern. There is plenty to celebrate. For most indicators, the trend is toward improvement, and for several—including infant and child death rates; uninsured rates; the immunization rate; teen pregnancy rates—the data are truly encouraging. However, there is also cause for heightened concern and strong action. For several indicators—including child abuse and neglect; child abuse homicide; asthma; overweight in low-income children; the use of alcohol, tobacco, and illegal substances—the data reflect unnecessary and unacceptable risks to NC children and youth. When data are available, they indicate that racial disparities remain disturbingly wide.

The underlying messages are the same as those noted in prior Report Cards. North Carolina's child health outcomes are not a matter of happenstance, nor are they inevitable. Our results—good, bad, or indifferent—invariably mirror investments made by the NC General Assembly, and the hard work and perseverance of coalitions that include state and local agencies, providers, and child/family advocates. Regrettably, the state budget crisis over the past few years has seriously limited the growth in these investments, and progress on many indicators is showing signs of slowing or reversing.

A recent landmark decision by the NC Supreme Court has confirmed children's constitutional right to the opportunity for a sound, basic education. It must be recognized that failure to deal with health issues robs children of this opportunity. Children cannot maximize their educational potential if they have been poisoned by lead, are dealing with the pain of tooth decay, are living with untreated developmental delays or chronic illnesses, or do not feel safe at home.

Our children are 20% of our population, but they are 100% of our future. They will soon be our leaders, our producers, and our consumers. Now is the time to make the investments that will assure a bright future for our state.

Grades and Trends

Grades are assigned to bring attention to the current status of each indicator, and are based on a general consensus among the sponsoring organizations. A indicates that the current status is "very good"; B is "satisfactory"; C is "mediocre"; D is "unsatisfactory"; F is "very poor".

Trends are represented by arrows: \uparrow indicates the data are improving; \downarrow indicates the data are becoming worse; \rightarrow indicates little or no change from the reference year. Regardless of the grade, the trend reminds us if progress is being made, and progress should be our goal in every case.

Tom Vitaglione (NCCAI), Kristen L. Dubay (NC IOM), and Kristie Weisner Thompson (NC IOM) led the development of this publication, with valuable contributions from many staff members of the North Carolina Department of Health and Human Services (DHHS).

North Carolina Child Advocacy Institute

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Health Indicator	Current Year	Benchmark Year	Δ		Grade & Trend	
					-orrel	
Insurance coverage ¹	2004	1999				
Health Choice enrollment in December (age 0-18)	131,497	53,934	+ 144%	Α	\wedge	
Medicaid enrollment in December (age 0-18)	674,885	456,032	+ 48%	Α	\uparrow	
% of children (age 0-18) below 200% of poverty with	87.7	65.8	+ 33%	Α	\wedge	
public insurance (Medicaid or Health Choice)						
% of all children (age 0-17) uninsured	11.1	13.9	- 20%	В	B 个	
Medicaid Preventive Care ²	FY 03-04	FY 98-99				
% of Medicaid-enrolled children (age 0-18) receiving	69.7	68.1	+ 2%	В	\rightarrow	
preventive care						
Infant Mortality ³	2004	1999				
# of infant deaths per 1,000 live births:						
All	8.8	9.1	- 3%	В	\rightarrow	
White	6.2	6.8	- 9%	В	\wedge	
Other races	15.6	14.8	+ 5%	D	\checkmark	
Low Birth-Weight Infants ⁴	2004	1999				
% of infants born weighing 5 lbs., 8 ozs. or less:						
All	9.1	8.9	+ 2%	D	\rightarrow	
White	7.4	7.2	+ 3%	D	\rightarrow	
Other races	13.4	13.1	+ 2%	F	\rightarrow	
Immunization Rates ^₅	2004	1999				
% of children with appropriate immunizations:						
At age 2	82.9	81.8	+ 1%	Α	\rightarrow	
At school entry	99.1	99.4	0%	Α	\rightarrow	
Communicable Diseases ⁶	2004	1999				
# of newly reported cases:						
Congenital Syphilis	13	21	- 38%	В	\wedge	
Perinatal HIV/AIDS	0	4	- 100%	Α	\wedge	
Tuberculosis (age 0-19)	42	33	+ 27%	С	\downarrow	
Vaccine-Preventable Communicable Diseases ⁷	2004	1999				
# of reported cases (ages 0-19):						
Measles	2	0	+ 200%	Α	\rightarrow	
Mumps	1	3	- 67%	Α	\rightarrow	
Rubella	0	8	- 100%	Α	\uparrow	
Diptheria	0	0	0%	Α	\rightarrow	
Pertussis	70	84	- 17%	В	\uparrow	
Tetanus	0	0	0%	Α	\rightarrow	
Polio	0	0	0%	Α	\rightarrow	

Health Indicator	Current Year	Benchmark Year	Δ		ade rend	
Environmental Health ⁸	2004	1999				
Lead: % of children (age 12-36 months):						
Screened for elevated blood lead levels	39.1	30.4	+ 29%	С	\wedge	
Found to have elevated blood lead levels	1.3	2.3	- 43%	В	\wedge	
Asthma: % of children (Grade 7-8) who have:	2004	2000				
Reported asthma symptoms	na	28				
Diagnosed asthma	na	11				
Asthma: Hospital discharges per 100,000 children	2004	1999				
(age 0-14):	180.1	262.2	- 31%	В	в 🛧	
Dental Health ⁹	FY 04-05	FY 99-00				
% of children with untreated tooth decay (kindergarten)	22	23	- 4%	D	\rightarrow	
% of children with one or more sealants (Grade 5)	42	34	+ 24%	В	\uparrow	
% of Medicaid-eligible children:	2004	1999				
Ages 1-5 who received dental services	26	16	63%	D	\wedge	
Ages 6-14 who received dental services	43	31	39%	D	· 个	
Ages 15-20 who received dental services	29.5	18	64%	D 1		
Early Intervention ¹⁰	2004	1999				
# of children (ages 0-3) enrolled in early intervention services to reduce effects of developmental delay, emotional disturbance, and/or chronic illness	11,270	6,873	+ 64%	В	\uparrow	
Child Abuse & Neglect ¹¹	FY 03-04	FY 98-99				
# of children:						
Receiving assessments for abuse & neglect	113,557	104,329	+ 9%	I	Not	
Substantiated as victims of abuse & neglect	27,310	32,115	- 15%	Gr	aded	
	2004	1999				
Confirmed deaths due to abuse	31	21	+ 48%	F	\downarrow	
Child Fatality ¹²	2004	1999				
# of deaths per 100,000 children (age 0-17)	77.7	86.7	- 10%	В	\wedge	

Health Indicator	Current Year	Benchmark Year	Δ		ade rend
	0004	4000			
Deaths Due to Injury ¹³	2004	1999			
# of deaths (age 0-17):	100	454	0.50/	•	
Motor Vehicle-related	192	154	+ 25%	C	Ý
Drowning	13	33	- 61%	В	$\leftarrow \rightarrow \leftarrow \leftarrow \leftarrow \leftarrow$
Fire/Burn	19	13	+ 46%	С	Ý
Bicycle	6	12	- 50%	В	T
Suicide	23	33	- 30%	С	T
Homicide	51	54	- 6%	D	\uparrow
Firearm	39	50	- 22%	D	\wedge
Alcohol, Tobacco & Substance Abuse ¹⁴	2003	1997			
% of students in Grades 9-12 who reported using the					
following in the past 30 days:					
Cigarettes	24.8	35.8	- 31%	D	\uparrow
Marijuana	24.3	24.9	- 2%	F	\rightarrow
Alcohol (incl. beer)	39.4	42.7	- 8%	F	$\rightarrow \\ \uparrow \\ \uparrow$
Cocaine	2.7	3.0	- 10%	С	\wedge
Physical Activity ¹⁴	2003	1997			
% of students in Grades 9-12 who exercised at least	61.2	55.3	+ 11%	С	\wedge
20 minutes a day, at least 3 days in the past week					
Overweight ¹⁵	2004	1999			
% of low-income children who are overweight:					
Age 2-4	14.9	12.3	+ 21%	D	\checkmark
Age 5-11	23.8	17.8	+ 34%	F	\checkmark
Age 12-18	27.2	22.5	+ 21%	D	\checkmark
Teen Pregnancy ¹⁶	2003	1998			
# of pregnancies per 1,000 girls (age 15-17):					
All	36.0	54.1	- 33%	С	\uparrow
White	28.2	41.8	- 33%	С	\uparrow
Other races	52.5	81.1	- 35%	С	\uparrow
La faca a					

Notes:

1. Insurance Coverage. NC's Medicaid Program and Health Choice Program have both been recognized for their innovative coverage of children. *Covering Kids*, a community-based outreach initiative sponsored by the NC Pediatric Society Foundation has led to large increases in enrollment in both programs. These enrollment increases are reflected in the most recent census figures, which indicate significant declines in the percentage of uninsured children in the past five years. While the economic downturn and continued loss of employer-based insurance has kept the state's overall uninsured rate above 16%, NC's investments in public insurance have reduced the children's uninsured rate to the national average, 11.1%. Access to care through insurance is a critical underpinning of children's health status. To affect a balance between coverage and costs, the General Assembly has recently enacted changes in both Medicaid and Health Choice and their results must be monitored closely.

2. Medicaid Preventive Care. Over the past decade, enormous progress has been made in assuring that Medicaid-enrolled

children receive preventive care on a continuous basis. Though the current rate of almost 70% is good, there has been very little progress in the past five years. Community Care of North Carolina, which links children with primary care providers, is an excellent program that continues to expand. Hopefully, this expansion will soon lead to improved rates of preventive care.

3. Infant Mortality. The infant mortality rates of 8.2 in both 2002 and 2003 were the lowest ever recorded in NC. Following a national trend, the rate increased by 7% to 8.8 in 2004. Though this still represents a remarkable 12% reduction in the infant mortality rate in the past decade, the beginning of an upward trend is cause for concern. (And NC continues to rank in the mid-forties among the states.) NC DHHS already has in place a State Infant Mortality Collaborative, which is focusing on the problem. Attention is being given to the overall health of women as a determining factor. In addition, significant attention is being focused on the wide disparity in the rates for whites and other races. There is also concern that the trend for Hispanics is increasing.

4. Low Birth-Weight Infants. Low birth-weight is a serious component of infant mortality, and is also associated with childhood developmental delays. Regrettably, this indicator has remained intractable over the years. Efforts to reduce this problem are shifting to the preconception period. It has been noted that women with a history of positive health behaviors prior to pregnancy have better birth outcomes. School health curricula and awareness campaigns can play a big role in this regard. The wide disparity between whites and other races remains a cause for great concern.

5. Immunization Rates. Federal reports indicate that North Carolina's immunization rate at age two has been among the best in the nation for the past several years. This true success story is directly attributable to a decision by the NC General Assembly to make vaccines available at low or no cost, and to a statewide initiative, which benefits from the participation of public and private primary care providers.

6. Communicable Diseases. A decade-long NC DHHS initiative has dramatically reduced the number of newly-reported congenital syphilis cases and it is hoped this progress will continue. Though more infants are being born to women who are HIV+, it is truly remarkable that the transmission of HIV/AIDS from mother to child during birth has become a relatively rare event (0 transmissions in 2004). This is due to a statewide system of voluntary testing, counseling, and drug intervention for which public and private providers should be proud. Regrettably, tuberculosis has rebounded in children and youth in NC, likely due to the entry of migrants and immigrants with the disease.

7. Vaccine-Preventable Communicable Diseases. Due to the development of vaccines and a statewide surveillance system guided by NC DHHS, these diseases are no longer the childhood afflictions they used to be. Tetanus, diphtheria and polio have been virtually eliminated. Cases of measles and mumps are rare and contained. The persistence of pertussis warrants careful monitoring. A fourth consecutive year with no cases of rubella reported is testimony to the work of local health departments providing immunization education and services, particularly focused on new immigrant populations.

8. Environmental Health. The percent of children ages 12-36 months screened for blood lead levels has increased significantly in the past five years due to a statewide awareness initiative and the participation of private physicians and local health departments' WIC Programs. However, only 39% of the target children were screened in 2004, a disappointingly low percentage given the adverse effects of elevated blood lead levels (defined as 10 micrograms per deciliter or greater) on child development. Conversely, the percent of screened children found to have elevated levels has declined dramatically to its lowest point ever in NC, largely due to awareness campaigns and the continued reduction in exposure to products containing lead. The NC Department of Environment and Natural Resources' plan to eliminate childhood lead poisoning by 2010 deserves both public and private support. The NC School Asthma Survey was conducted in 1999-2000 on most seventh- and eighth-graders and produced for the first time relatively accurate estimates of asthma prevalence. The data confirm that asthma is the leading chronic illness among our school-age children, with few urbanrural and racial differences in prevalence. Recent comparable survey data are not available, but a new health survey (CHAMPS) sponsored by NC DHHS should provide such data next year. The decline in the hospital discharge rate reflects the efforts of the NC Medical Society Foundation and Community Care of North Carolina to educate primary care providers in the management of asthma

9. Dental Health. Data from surveys conducted by the DHHS Oral Health Section show little improvement in the dental health of children entering kindergarten, with 22% having untreated tooth decay. Awareness regarding the effectiveness of fluoride varnish for young children is growing, which hopefully will reduce the prevalence of tooth decay at school entry. Happily, the percent of school-age children with the protection of sealants continues to grow. However, although access to dental care for Medicaid-enrolled children has grown, it remains disappointingly low.

10. Early Intervention. Program caseloads continue to increase dramatically, and North Carolina's collaborative early intervention services system continues to receive national acclaim. Despite these impressive enrollment numbers, program administrators estimate that less than 60% of the target population is being served. Under federal requirements, children less than three years of age who are confirmed victims of maltreatment are now part of the system's target, and waiting lists have been growing. Administrators have reorganized the system in hopes of expanding capacity, and the General Assembly has recently increased appropriations by \$5 million. Hopefully, the system will be able to keep pace with the growing service need.

11. Child Abuse and Neglect. To deal with reports of maltreatment more efficiently and effectively, and with hopes of reducing both initial and repeat occurrences of abuse and neglect, NC DHHS is implementing a Multiple Response System (MRS). MRS is an effort to reform the entire continuum of child welfare in North Carolina using family-centered principles of partnership. Thus, an accurate comparison of data over time is not possible. However, it should be noted that the number of children substantiated as victims of abuse and neglect has hovered near 30,000 annually for many years. In communicable disease terms, child maltreatment is endemic in our society. A Child Maltreatment Prevention Task Force sponsored by the NC Institute of Medicine will soon release its recommendations. These should receive considerable attention. Tragically, deaths due to child abuse continue to occur about once every two weeks and increased significantly in the past five years. Child abuse deaths represent more than half of all child abuse homicides.

12. Child Fatality. After declining to the lowest level ever reported in 2003, the rate for 2004 rose slightly. Nevertheless, due to legislative investments and the strengthening of child safety laws, the child fatality rate has declined by 10% in the past five years and 20% in the past decade. The NC Child Fatality Task Force, as well as state and local review teams, continues to explore ways to prevent child deaths.

13. Deaths Due to Injuries. This is the primary cause of death in children older than one year of age. After a decade-long decline, the number of motor vehicle-related deaths jumped in 2004, and this should come under careful scrutiny. Though the numbers are relatively low, more awareness campaigns are needed to promote the vigilance needed to prevent unintentional deaths due to drowning, fires, etc. Cases of suicide and homicide, though in decline, are a continuing tragedy.

14. Alcohol, Tobacco, Substance Abuse and Physical Activity. These data, which indicate improvement over the past six years, are derived from the biennial Youth Risk Behavior Survey conducted by the NC Department of Public Instruction, in cooperation with the federal Centers for Disease Control and Prevention. However, when compared to the 2001 survey, it appears that progress in reducing the use of cigarettes and alcohol has slowed. Though there are some questions regarding the validity of the survey process, these data indicate a need for continued efforts to reduce the risk-taking behaviors of our youth. NC DHHS and the NC Health and Wellness Foundation are investing in initiatives that show great promise. Recent legislative appropriations for school nurses and social workers should lead to further improvements.

15. Overweight. This is conservatively defined as a body mass index equal to or greater than the 95th percentile using federal guidelines. This area is receiving increased attention. The DHHS-sponsored NC Health Weight Initiative, as well as an array of investments made by the NC Health and Wellness Foundation, deserve consideration and support. New laws and policies promoting physical activity and restricting the availability of certain foods/drinks in schools should bring positive results. Hopefully, the data, which continue to worsen, will begin to show improvement. This is critical because childhood obesity can lead to adult health problems, such as high blood pressure, heart disease, and diabetes. While the children represented in these data are those who receive services in local health departments or school health centers and may not be representative of the state as a whole, these data send an important signal that must be heeded.

16. Teen Pregnancies. The national decline in teen pregnancies is being experienced in NC as well. While the data are encouraging, it is clear that more progress must be made in this area. Though improving, the wide disparity in rates between whites and other races is of particular concern.

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Readers' Forum

To the Editor:

The July/August 2005 issue of the *North Carolina Medical Journal*, which was devoted to nutrition in long-term care facilities, struck an interesting note with me.

As Lieutenant Governor in the Kiwanis International organization, I visit many of the clubs in my area of North Carolina. One club that I especially like to visit is the Catawba Valley Golden K Club. This is a club composed of members 55 years of age and older. It meets on a regular weekly basis at noon in a large, wellappointed retirement home in Hickory (Pinecrest Manor).



Therefore, at least once a week, a large number of noninvolved people sample, taste, and "evaluate" the food in this long-term care facility. Every member of the club would rate it as outstanding!

I would like to be bold enough to suggest that local civic clubs, such as Kiwanis, might be helpful in "monitoring" nutrition in long-term care facilities.

W. Grimes Byerly, MD Lt. Governor Division 4 Carolinas District of Kiwanis Hickory, NC

To the Editor:

I found the issue on Innovations in Community-Based Primary Care to be particularly interesting. I read a few of the main articles and enjoyed them, but I was disappointed to find no mention of the family. With its diverse



culture, etc., the family has and will be an important element in any primary care system as long as we go beyond the biomedical model, especially for care of "chronic disease and conditions."

> Jack Medalie, MD Dorothy Jones Weatherhead Professor and Chair Emeritus Department of Family Medicine Case Western University Cleveland, OH

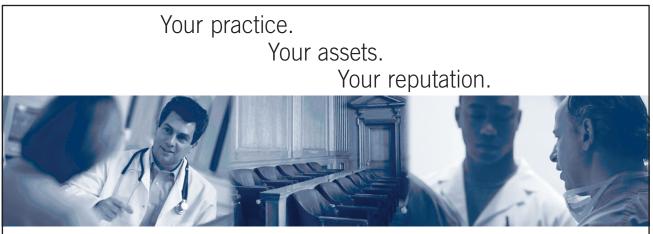




Contact Adrienne R. Parker, Business Manager 919/401-6599, ext 28; adrienne_parker@nciom.org Coming in the November/December 2005 issue of the

North Carolina Medical Journal

a look at Access to Dental Care



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Running the Numbers

A Periodic Feature to Inform North Carolina Healthcare Professionals about Current Topics in Health Statistics

From the State Center for Health Statistics, North Carolina Department of Health and Human Services www.schs.state.nc.us/SCHS

North Carolina Child Deaths from Violence in 2004: Data from the National Violent Death Reporting System

The National Violent Death Reporting System (NVDRS) is a congressionally mandated, state-based national repository of statistics that describe violence resulting in death. Its purpose is to quickly record and report standardized information on violent deaths, including suicides, homicides, unintentional deaths from firearms, and deaths of undetermined intent (many of which are the result of violence). Seventeen states, including North Carolina, are now funded and daily send more than 250 de-identified data items to the NVDRS. It is planned for all 50 states to eventually participate, making this a truly nationwide database.

The North Carolina Violent Death Reporting System (NC-VDRS) is operated by the North Carolina Division of Public Health, Injury and Violence Prevention Branch. Collection of data on deaths from violence to North Carolina residents began on January 1, 2004. The primary purpose of the NC-VDRS is to provide data to promote and support violence prevention strategies designed to reduce the number of people of all ages who die from assaults or self-inflicted injuries or from the accidental discharges of firearms. NC-VDRS data are obtained from public records (i.e., death certificates, medical examiner records) and nonpublic records (i.e., several different types of law enforcement reports on the victims and suspects prior to the completion of due process). The NC-VDRS has stringent privacy and confidentiality procedures to protect the nonpublic data. Collecting information from these multiple data sources allows us to describe the victims and suspects in each event and their relationship(s) and to document the methods and circumstances that led to these deaths.

Data Available from the NC-VDRS

The NC-VDRS releases provisional data on the first six months of each calendar year in a technical report every February/March of the following year. It releases an annual report for the previous calendar year in late October of the following year. The annual report for 2004 NC-VDRS data will be posted on the Injury and Violence Prevention Branch page of the NC Division of Public Health web site in late October 2005 (www.ncpublichealth.com).

NC-VDRS as Part of a North Carolina Child Maltreatment Surveillance System

The NC-VDRS is a valuable source of information to help us understand and prevent violence in children. Death is a most serious consequence of child abuse and neglect. Not every act of child maltreatment results in death, and not every child death in the NC-VDRS data base is the result of abuse or neglect. However, the availability of data from the NC-VDRS allows us to more quickly and carefully assess factors associated with deaths from violence in one of our state's most vulnerable populations, its children.

Selected Findings on Violent Deaths in Children from the NC-VDRS, 2004

In 2004, 87 North Carolina children under the age of 18 were killed from acts of violence. In contrast to the profile of violent deaths in North Carolina adults where there are almost twice as many suicides as homicides, more children died in 2004 from homicide than all other types of violence combined. Fifty-four children died from homicide in 2004 (42 boys; 12 girls). Table 1 shows the distribution of these homicide deaths by age. Half of these homicides (50%) occurred among African American children, 48% among white children, and 2% among American Indian children. Almost all of the homicides of North Carolina children occurred in the non-Latino population (96%).

Twenty-four children and teenagers died from self-inflicted injuries in 2004 (20 boys; 4 girls). Table 1 shows the distribution of these suicide deaths by age. Almost three-fourths of the suicides occurred among whites (71%, n = 17), with 29% (n = 7) among African Americans. There were no youth suicides recorded for North Carolina

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Age Group	Suicide ¹		Homicide ²		Unintentional Firearm ³		Undetermined Intent		Total
	Ν	%	Ν	%	N	%	N	%	N
<1	0	0	10	18.5	0	0	0	0	10
Ages 1-4	0	0	15	27.8	1	25.0	1	20.0	17
Ages 5-9	0	0	1	1.8	0	0	1	20.0	2
Ages 10-14	9	37.5	13	24.1	2	50.0	0	0	24
Ages 15-17	15	62.5	15	27.8	1	25.0	3	60.0	34
Total	24	100.0	54	100.0	4	100.0	5	100.0	87

1 A death resulting from the intentional use of force against oneself. This includes "Russian roulette" and assisted suicide involving only passive assistance to the decedent, such as supplying information or the means to complete the act.

2 A death resulting from the intentional use of force or power, threatened or actual, against another person, group, or community (not including acts of war). This includes "justifiable homicide."

3 A death resulting from a penetrating injury or gunshot wound from a weapon that uses a powder charge to fire a projectile when there was a preponderance of evidence that the shooting was not intentional. This includes a child less than the age of six who shoots himself or another person.

Latino residents in 2004. Four children died from the unintentional discharge of a firearm. The intent of five deaths in children under the age of 18 could not be determined by the medical examiner.

All but three of the 29 deaths from violence in children under age 10 were homicides. The exceptions were a three-year-old who died from an unintentional firearm injury, and a one-year-old and a five-year-old who died from undetermined intents.

For the 10 infants under age one who died from homicide, their deaths were the result of shaking (3); personal weapons, e.g., fists or kicking (2); intentional neglect, e.g., starving a baby (2); a blunt instrument (1); or an unknown weapon (2). According to narrative descriptions obtained from Medical Examiner data, some of the children had signs of prior abuse at the time of their deaths and most were killed by a parent or caretaker.

For the 15 children ages one to four who died from homicide, their deaths were the result of personal weapons (8), shaking (1), blunt instrument (1), drowning (2), firearm (1), or hanging/strangulation/suffocation (2).

For the two children ages five to nine who died from violence—ages when children begin to be more exposed to people outside the home—one death was a homicide and the intent of the other could not be determined by the Medical Examiner.

Among the 24 children ages 10 to 14 who died from violence, there were nine suicides, 13 homicides, and two unintentional firearm injuries. Among the 34 adolescents ages 15 to 17 who died from violence, 15 were suicides, 15 were homicides, one was from unintentional firearm discharge, and three were from deaths of undetermined intent. In this age group, firearms were responsible for 24 of the 34 deaths from violence, including 53% of the suicides and 87% of the homicides.

Conclusion

Preserving and protecting our children's health is most effective when our programs and policies are based on timely and accurate information. Because the data collected in the North Carolina Violent Death Reporting System are consistent across the multiple data sources from which they are obtained, we will be able to accurately detect changes over time. As a result, these data can be used to monitor child abuse and maltreatment over time and to formulate and evaluate programs and policies.

Contributed by Catherine (Kay) Sanford, MSPH, Stephen W. Marshall, PhD, and Tammy Norwood, BS North Carolina Violent Death Reporting System, North Carolina Division of Public Health

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The North Carolina Institute of Medicine Since January 2002, Publisher of The North Carolina Medical Journal

In 1983 the North Carolina General Assembly chartered the North Carolina Institute of Medicine as an independent, nonprofit organization to serve as a nonpolitical source of analysis and advice on issues of relevance to the health of North Carolina's population. The Institute is a convenor of persons and organizations with health-relevant expertise, a provider of carefully conducted studies of complex and often controversial health and healthcare issues, and a source of advice regarding available options for problem solution. The principal mode of addressing such issues is through the convening of task forces consisting of some of the state's leading professionals, policy makers and interest group representatives to undertake detailed analyses of the various dimensions of such issues and to identify a range of possible options for addressing them.

Members of the North Carolina Institute of Medicine are appointed for five-year terms by the Governor, and each task force convened by the Institute typically includes at least one-third of its membership from among the appointed members. Topics to be addressed through task force efforts are chosen following requests from the Governor, the General Assembly or agencies of state government. In some cases, topics are selected on the basis of requests from a number of stakeholder organizations across the state where this type of analytical process is considered to have potential value.

The North Carolina Institute of Medicine assumed the role of publisher of the *North Carolina Medical Journal* in January 2002 through an agreement with the North Carolina Medical Society, which founded the Journal in 1845. The Institute views the *North Carolina Medical Journal* as an extension of its mission. The Journal provides a forum for stakeholders, healthcare professionals, and policy makers and shapers to study and discuss the most salient health policy issues facing our state. Like many states, North Carolina is grappling with issues such as an increasing number of uninsured, the unmet health needs of the growing Latino population, a critical shortage of nursing personnel, the health risks of tobacco and obesity, rising prescription drugs costs, mental health system reform, the increasing societal burden of chronic illness care, the threat of bioterrorism and the necessity of assuring adequate public health preparedness—all in the midst of an economic downturn. Each of these issues presents unique challenges to healthcare providers and state policy makers. Yet, a fully implemented task force to consider each of these issues is not feasible. The Journal makes it possible to present an organized and balanced overview of some of these issues, six times per year, and allows interested persons the opportunity to engage in the ongoing discussion of these issues throughout the year. The Institute hopes that our readers of the *Journal* will, in this way, become involved in the continuing debate about the most promising avenues for assuring the highest standards of health and healthcare for all North Carolinians.

North Carolina Institute of Medicine



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- Please include the writer's full name, address, and daytime phone number. Letters may be edited for clarity or space.

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Southeastern **Regional Medical Center becomes** nursing classroom UNCP four-year nursing program to

be conducted at the Medical Center

LUMBERTON - Southeastern Regional Medical Center will provide a working environment for students enrolled at the University of North Carolina at Pembroke.

The program facilities will be located at the current SRMC Corporate Services Building and provide 7,000 square feet of clinical settings, classrooms, computer labs, and offices.

"UNCP's nursing program will assist our region by graduating top-quality nurses," Chancellor Allen Meadors said. "The nursing

field is a noble, caring profession, and it is critical to help resolve the increasing nursing shortage

"We at SRMC are excited about the approval of the UNCP fouryear nursing program," Chief Executive Officer and President Luckey Welsh said. "Our citizens will benefit for years to come because of this collaborative

The nursing program is expected to add 100 BSN graduates annually to the Lumberton area.

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UNIVERSITY OF NORTH CAROLINA

DEPARTMENT OF NURSING

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