

Financing Newborn Screening Systems: US Experience

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Abstract

Newborn screening (NBS) in the United States (US) has existed since the early 1960s and is required in all 51 state jurisdictions. It is generally recognised that NBS provides a significant public health benefit by preventing or markedly decreasing the adverse medical consequences of conditions included in the screening panel. There is currently no US national NBS policy, so instead there are 51 independent state programmes that vary widely in their policies, infrastructures, procedures and services. Not surprisingly, US NBS programme costs and methods of financing also vary. Surveys have increasingly found a reliance on fees to pay for screening tests, short-term follow-up and other parts of state NBS systems. This article reviews some of the current US NBS financing issues and methodologies.

Ann Acad Med Singapore 2008;37(Suppl 3):97-100

Key words: Fees, Financing, Newborn screening, Paediatrics, Screening

Introduction

Newborn screening (NBS) for phenylketonuria (PKU) began in the US in the early 1960s.¹ The intended impact of screening was to reduce or eliminate the mental retardation known to result from PKU, and thus, to keep patients from being institutionalised at the government's expense. As NBS began in each state, a legislative requirement to screen all newborns was usually enacted in order to ensure full population coverage and to define sustainable financing from government funding. At the time, unfunded mandates from state governments were rare and it was relatively easy to develop an overall government cost savings justification for NBS. Savings arose since PKU patients were routinely housed in government mental institutions. Annual institutionalisation expenses for a single patient are significant and the magnitude of the expenses multiplies over a lifetime. Therefore, detection of relatively few cases of PKU results in overall government cost savings when testing costs are compared to the costs of institutionalisation over a lifetime.²

As state NBS programmes expanded to include other conditions in the 1960s and 1970s, the financing issues became more complex. The primary funding issues centred on the fact that all screened conditions did not impact government spending to the same degree. Some screened

conditions did not necessarily result in institutionalisation, so government costs savings were not as obvious. The result was a gradual move towards NBS programmes that could be sustained without government financial support. Thus, state public health departments began to consider NBS fees in the late 1960s, and now almost all programmes have some level of fee.² Figure 1 provides a graphical look at the fees that exist in state NBS programmes today (discussed later).

NBS screening in the US originated at the state level and there has never been a national NBS policy. Despite the lack of national NBS policy, there has been sporadic federal financial support for state NBS programmes, often as part of genetics funding activities. In the mid-1970s, there was specific federal funding legislation that applied directly to genetic disease screening. However, in 1981 genetic diseases became a part of block grant funding to the states, and newborn screening and genetic service activities became a part of the Health Resources and Services, Maternal and Child Health Branch (HRSA/MCHB) Special Projects of Regional and National Significance (SPRANS). In the late 1980s, special supplemental SPRANS funds were used to encourage universal NBS for sickle cell diseases to help enact a 1987 consensus recommendation from the National Institutes of Health.²

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Other SPRANS projects have indirectly impacted NBS over the years including genetics planning and implementation grants and grants for various state data projects. Since 1999, HRSA/MCHB has funded the National Newborn Screening and Genetics Resource Center (NNSGRC) through a cooperative agreement with the University of Texas Health Science Center at San Antonio.³ Regional cooperation/collaboration for NBS follow-up activities has also been encouraged by HRSA/MCHB. During the 1980s, HRSA/MCHB funding supported a national collaboration that resulted in the ‘Council of Regional Networks for Genetic Services.’ Since 2004, HRSA/MCHB cooperative agreements have supported 7 redefined regional collaboratives for genetics and newborn screening and a national coordinating centre in an effort to continue to enhance clinical genetic services and other family support needs in geographic areas lacking such resources.⁴

The specifics of NBS financing over time can be tracked through various survey reports. A 1983 survey reviewing the impact of reduced federal support of genetic services showed that block grant funding had resulted in prioritisation of NBS by public health departments to in order to preserve their funding.⁵ Those states that were not charging a fee for NBS then, were under pressure to begin one, and by 1985, about half of all programmes were collecting a NBS fee.⁶ By 2001, 13 NBS programmes reported that fees were their sole funding source and 19 other NBS programmes reported fee revenue comprised at least 60% of their newborn screening revenue.⁷ In 2006, fees existed in 45 NBS programmes⁸ and today, the number stands at 47.⁹

Methods

The usual method for fee collection is by charging for a screening ‘kit’ that includes the filter paper collection device and accompanying data submission form(s). A mailing envelope into which multiple forms may be placed often accompanies kit orders, although mailing costs may or may not be included in the kit cost. Lancets and other specimen collection supplies are usually not included in the kits and must be supplied by the specimen collection facility. Kit costs usually include screening laboratory costs and may include certain other system costs including programme administration, public relations, education, and/or screening follow-up among others. In order to speed up the process of specimen transport, there is a trend towards courier services, and this cost is sometimes included in the kit pricing. The components included in NBS fee calculations can be extensive and complex, and fee amounts vary accordingly.⁹

Kit charges are usually payable at the time the kit order is filled. Since kits are ordered in advance of birthing,

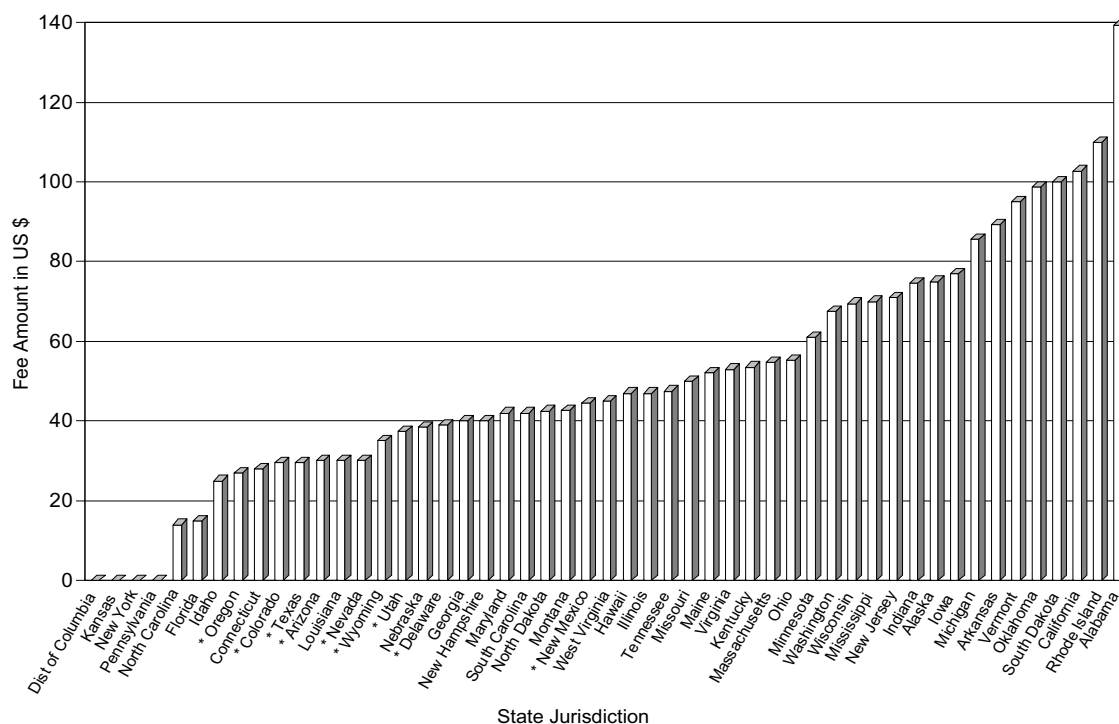
payments may be extended over a certain time window (varies from 30 to 120 days) to facilitate cash flow at the specimen collection facility (where costs are usually recovered from third party insurers). A limited number of NBS programmes bill specimen submitters periodically (usually monthly) based on specimens received at the screening laboratory. In cases where 2 or more specimens may be required by NBS policy, the initial kit charge often includes the cost of the second or subsequent kits.

Private health insurance usually includes payment for NBS as part of maternity benefits and public welfare insurance (Medicaid) also includes NBS. While it is usually the submitter who must recover insurance costs, at least one NBS programme bills insurers directly. Since Medicaid payments are state regulated, reimbursement methods and amounts vary. In a limited number of states, Medicaid funds are transferred directly to the NBS programme, but in most cases, these payments are part of negotiated hospital diagnosis related grouping (DRG) agreements. For this reason, it is sometimes difficult to increase NBS kit or service fees since the DRG agreements cover specified time periods and a NBS cost increase during the contract period may not translate to a corresponding DRG increase. In no case does inability to pay for state-required NBS services at the patient level prevent screening. Various mechanisms exist to accommodate non-payment including averaging such occurrences into the overall fee basis.

Results

As of August 1 2008, 47 state NBS programmes report collecting a fee for NBS (see fig. 1).⁹ Nine programmes require 2 screens on each newborn, as indicated by an asterisk in the table, and for each, the fee given is for an initial screen. In cases where an initial fee is not easily separated from the two-screen fee, the fee has been halved to approximate the cost of a single initial screen. In Arizona, there is a higher fee of \$10 for the second screen and in Colorado the second screen costs \$10 less. In at least 2 states, a small surcharge is included in the fee to accommodate additional programme costs and in at least 1 state, newborn hearing screening is included in the screening fee. The average initial screening fee for those charging a fee is \$51.89 (with the adjustments noted for those with multi-specimen fees), although not all programmes provide identical services nor do they have identical screening panels. Current fees for US programmes can be found at <http://www2.uthscsa.edu/nnsis/> (accessed September 23, 2008).

Fee income is usually processed in one of two ways – either as a deposit to the state’s general revenues or as income for dedicated programme use. NBS programmes



* Indicates state that requires two screens on all newborns (fee plotted is half of total fee if fee includes two screens)

Fig. 1. Fee amounts currently⁹ charged in US newborn screening programmes in ascending order.

may have to compete for the use of general revenue funds along with other government programmes, while competition for dedicated funds is usually not necessary. In either case, political considerations have been known to affect fund usage.¹⁰ In cases where a contracted laboratory provides screening services, the fee may be collected by that laboratory. The contract may require payment of part of the fee to the NBS programme for follow-up/education and related administrative costs. Most fees do not include costs for start-up of new screening procedures. Lack of start-up funding usually means that a separate request to the state legislature is needed to add expensive technologies for screening expansion. Thus, NBS expansion in a government setting is often slower than in the private sector (other factors may also contribute such as lower salaries received in the government sector and lack of trained personnel).

Discussion

At the national level, most NBS funding comes from fees with limited augmentation from federal block grant funds and legislative appropriations. The US General Accounting Office (GAO, now Government Accountability Office) reported that in 2001, 64% of 2001 NBS programme funds came from fees, 5% from the Maternal and Child Health Services block grant, and 19% from other state funds.⁸ A

2007 survey confirmed that 90% of US NBS programmes had a fee, 61% obtained some funding from the federal maternal and child health block grant programme, and 33% obtained some support from state general revenues, although the relative amounts were not reported.⁷ The GAO Report also noted that laboratory costs outweighed non-laboratory costs approximately 2 to 1 in 1999.⁸ NBS programme expansions have likely caused this ratio to shift towards increased non-laboratory costs since larger numbers of conditions are being simultaneously detected that require additional follow-up and education.²

Many US NBS systems continue to lack extensive long-term tracking and comprehensive education programmes,¹¹ and most provide little or no funding for medical interventions or counselling.¹² Some programmes include payment (or partial payment using a sliding fee schedule based on family income) for PKU formula, but little else. As programmes have expanded, payment for other medical interventions (including specialty care, metabolic formulas and foods, drugs, counselling, and surgical interventions) have been identified as major policy considerations, but financing them as part of NBS remains controversial. There are special public assistance programmes for children and families with special health care needs, including those related to NBS conditions, but services and accessibility vary.⁸

While a national coding system for Medicaid reimbursement for medical laboratory services exists, there are currently no codes for NBS tests, and this has been cited as a hindrance to receiving reimbursements from insurance by some programmes. A national NBS fee coding model has been suggested for discussion,² but no actions have yet resulted. Recent Congressional action has resulted in the passage of authorisation legislation that directly impacts newborn screening,¹³ but until appropriations are approved, forward movement on the activities included in the Act will be limited. It is likely that appropriations for federally supported NBS activities will help in the national harmonisation process, but it is unlikely that services and fees will become uniform nationally without a stricter national policy in this regard. Regardless of the funding stream, NBS personnel remain dedicated to maintaining quality screening systems.

Acknowledgement

The author is supported by a grant from the U.S. Maternal and Child Health Bureau of the U.S. Health Resources and Services Administration (Grant No. U32MC00148).

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