tender mercies

A unique center in Kent treats the state's youngest drug addicts, and by all reports it's a remarkably cost-effective program. With hundreds of drug-affected babies born in Washington each year, why are so many beds going unused?

WRITTEN BY CAROL TICE PHOTOGRAPHS BY CHARLES PETERSON

A CAREFULLY SWADDLED DRUG-AFFECTED BABY SPENDS HER FIRST DAYS AT THE PEDIATRIC INTERIM CARE CENTER, HER WITHDRAWAL CAREFULLY MONITORED BY STAFF

At exactly 2 p.m. Kelly Denheyer loads up four small syringes with morphine and begins to make her rounds. A longtime pediatric nurse wearing cheery cartoon-printed scrubs and a broad smile, Denheyer strolls the quiet halls of the Pediatric Interim Care Center (PICC) in Kent,

INFANTS AT PICC FACE A DAUNTING ROAD—BUT WITH PROPER CARE, MOST DO WELL AFTER LEAVING THE CENTER

locates each of her charges in their pastel-toned, homey rooms and administers the meds one by one, sending morphine into tiny mouths as the babies lie bundled in their cribs. These heroin-addicted newborns need their medication delivered right on schedule to avoid withdrawal symptoms. Kala*, a fair-skinned, black-haired girl, wriggles a bit but sleeps right through her dose, while round-faced Isaac turns red and makes faint squawking noises of protest. A yet unnamed infant boy receives his dose with the shaking arms typical of infants in heroin withdrawal. The final patient, a tiny baby boy swaddled in yellow, dozes peacefully through the process.

All of PICC's 17 small patients are suffering withdrawal from drugs their mothers took while pregnant. For a little fewer than half of the 151 babies who spent time at PICC last year, that drug was heroin, the heroin substitute methadone or another opiate. The others were treated for withdrawal from the multiple drugs and alcohol their mothers used and abused while pregnant: methamphetamines, crack, cocaine or prescription drugs such as the strong opiates OxyContin and Dilaudid or antidepressants such as Prozac.

When babies exhibit withdrawal symptoms at birth but are otherwise healthy, some of them come to PICC through an unusual cooperative arrangement between PICC and hospitals around the state. They are referred by social workers from the Department of Social and Health Services (DSHS) or by a hospital worker, in most cases because parents are losing custody or their custody is up in the air. The babies spend from a few days to a few months at the center.

Though medical professionals from around the globe have studied PICC's program, so far it remains one of a kind—perhaps because no one else has wanted to take on the challenge of starting a similar program, which would involve raising significant funds, cultivating hospitals to gain their trust and recruiting a director willing to put in the hours needed to pull it off.

At PICC, the babies receive expert, 24-hour care designed to carefully manage their gradual withdrawal, while caregivers—either foster parents, or the biological parents or relatives who will take them home—are given training in their care. Most babies come as wards of the state, their birth mothers often impoverished and still grappling with addiction or homelessness, in no shape to care for them fulltime.

Recent months have brought both good news and bad to PICC. Though its effectiveness is widely praised, and it costs far less than hospital care (according to the center's annual report to DSHS, it saved the state more than $6 million last year alone), PICC has faced perennial struggles to retain the state funding that makes up roughly two-thirds of its $1.4 million annual budget. Donations make up the difference.

With hundreds of drug affected babies born each year (see sidebar), PICC's 27 beds could all be filled with infants—about 200 in a year. But while state funding increased in 2007 to cover care for 17 babies at a time—up from 13 in 2006—that still leaves 10 additional beds at PICC unfunded. So, to balance its budget, those beds are left empty.

The multiple reasons why PICC isn't fully funded are a complex stew of state politics and policies, as well as societal attitudes about addicts, families and babies. Another issue is new state guidelines for how hospitals assess and report on drug-affected infants. In PICC's annual report to DSHS, executive director Barbara Drennen notes that there is greater reluctance by hospital personnel to identify and refer drug-affected infants for treatment.

In addition, PICC medical director Dr. Peyton Gaunt says state social workers sometimes disregard doctors' recommendations for referral to PICC, sending the babies home instead.

PICC is the most intensive program in the state for treating drug-affected newborns, restoring their health and training families to care for them. But which babies belong at PICC and which should simply be sent home or should receive outpatient treatment is the subject of heated debate among hospital staff, DSHS social workers, PICC staff, state lawmakers, the state attorney general's office and others. Gaunt says that too often, the rights of parents win out—even parents with serious drug problems—while the needs of addicted babies come second.

In the 2007 annual report to DSHS, PICC detailed one example of what can happen when drug-affected babies are sent home with birth parents who are ill-equipped to deal with them.

"We recently had a baby come to us with a forcibly broken leg and terrible withdrawal symptoms," Drennen wrote. "We later found out that his mother, unable to control his irritability, has been dipping his pacifier into her methadone. It's a wonder the baby survived."

Without proper caregiver training, a stable home environment and the best medical care, Drennen says, these babies can grow up with lasting problems.

"Then," she says, "they hit the school system later, like a ton of bricks."

All of PICC's 17 small patients are suffering withdrawal from drugs their mothers took while pregnant. For a little fewer than half of the 151 babies who spent time at PICC last year, that drug was heroin.

PICC WAS FOUNDED IN 1990, on the heels of the crack epidemic, by longtime foster mothers Drennen and Barbara Richards, who'd both specialized in caring for premature and special-needs newborns. Originally opened in a converted doctor's clinic in Kent, the city where both founders lived, PICC in the beginning saw about 112 drug-affected infants a year.

Since Richards' retirement in 2000, Drennen has carried on, working 12-hour days, and staying on 24-hour call. She's the energy that powers PICC, a casually dressed, calm figure with frosted hair and the kind of wrinkles that come from smiling a lot. Often, she holds one of the babies while she works in her office, just steps from the babies' rooms. The phone

** All names of babies have been changed for confidentiality reasons.*

EXECUTIVE DIRECTOR BARBARA DRENNEN HOLDS ONE OF PICC'S 17 PATIENTS. WITH MORE FUNDING, THE CENTER COULD HELP EVEN MORE BABIES

rings, and she shifts the small bundle on her lap to take down details on an incoming baby. PICC takes every baby referred to it, Drennen says, though sometimes she has to ask a hospital to keep a baby a day or two longer, until a bed is available. "I'd never say 'no' to a baby," she says.

In 2006, Drennen concluded a $4 million capital campaign that funded a larger, graceful two-story building of brick and white wood, which opened near Kent Station that year.

It's an irony that just when PICC moved to a new space with room for more babies, the state's new guidelines have made it more difficult to get some drug-addicted babies to PICC for treatment. One group of babies who may be overlooked are those born with an addiction to speed-type drugs like meth.

Unlike babies in heroin withdrawal, with their obvious tremors and high-pitched agonized cries, these infants are harder to spot. They can seem like they're in perfect health, Drennen explains, sleeping a lot and loving to cuddle. But just as adult meth and cocaine users may go for days without eating, these babies want to do the same, and so can fail to thrive and grow. They need to be put on strict feeding schedules and patiently encouraged to suck properly. They often have gastrointestinal problems as well, caused by the drugs. As drugs such as meth exit a baby's system, these substances can cause sore and bleeding bottoms that also need special attention.

"Part of the issue," says PICC medical director Gaunt, "is that society as a whole somehow feels the natural course of events is babies should be staying with their biological parents, no matter what the circumstances."

But the new "Guidelines for Testing and Reporting Drug Exposed Newborns in Washington State," created in October to fulfill a federal law passed in 2003, are working against these babies. Where previously each hospital had its own policy on how to identify and when to test babies for drugs, and personnel could often use their own judgment, the new guidelines create a standard, statewide policy. In order to receive federal funds for child-abuse and -neglect programs, the Keeping Children and Families Safe Act requires states to come up with such standards to identify and meet the needs of infants affected by "illegal substance abuse or withdrawal symptoms resulting from prenatal drug exposure."

Advocates for children have found the new policy problematic. With the short hospital stay for most births, generally just 24 to 48 hours, withdrawal symptoms for a range of drugs may not be noticeable until after a mother departs with her baby, as they can take as long as four or more days to manifest, says Vangie Schasse, assistant nurse manager of the mother-baby unit at University of Washington Medical Center. And there's no "gut instinct" clause in the policy.

Then there's the focus on "illegal substance abuse," which leaves out prescription drugs. State Lieutenant Governor Brad Owen, a longtime PICC supporter, says PICC has expressed concerns that the policy will likely lead to fewer babies being identified in these categories, even though addiction to prescription drugs is on the rise. He also says PICC has had to battle for state reimbursement for babies born affected by legal drugs such as alcohol and prescription painkillers.

"The DSHS policy is horribly inadequate," says Owen, who notes that he plans to discuss it with legislators this year.

PICC, OWEN SAYS, has an unusual relationship with state government. On the one hand, the center enjoys support from many legislators—so much so that it's a line item in the state budget.

On the other hand, he says, that favored status has spawned resentment from social service agencies, and from some legislators who frown on entitlements. Drennen, an adept political player, has been able to rally support from Owen, the state attorney general's office and other influential parties, something Owen thinks other social service agencies may resent.

"The problem at DSHS," he says, "is it [PICC] wasn't invented here, and it's taking state money."

State Representative Dave Upthegrove (D-33rd), whose district includes PICC, agrees. He says he's fought both apathetic

BRIAN AND JEN CLINTWORTH ADOPTED HANNAH AND CALEB, WHO SPENT TIME AT PICC. THE TWINS ARE THRIVING TODAY

LONGTIME PEDIATRIC NURSE KELLY DENHEYER COMFORTS AN INFANT IN HER CARE

HOW BIG IS THE PROBLEM?

WITH LITTLE DATA, NO ONE REALLY KNOWS HOW MANY BABIES ARE BORN DRUG-AFFECTED

Part of the challenge of garnering legislative support for PICC is the incomplete data on how many Washington state babies are born drug-affected. Studies are few, and most are out of date. What does exist indicates drug-affected newborns may well be an underreported problem.

Data is collected in two categories—babies who merely test positive for drugs, and babies who are said to be drug-affected, showing obvious signs of drug withdrawal.

The Washington State Hospital Association's data, reported from state hospitals, indicated that more than 950 drug-affected infants were born in the state in 2006.

Hospitals are not required to report babies who test positive for drugs but don't have any symptoms. State governmental research organ the Washington State Institute for Public Policy estimated in 2002 that between 8,000 and 10,000 babies per year are exposed to illicit drugs out of more than 85,000 total births. Barbara Drennen of PICC says she's seen estimates of 12,000 or more.

Seattle-based Swedish Medical Center, which delivers more babies than any other hospital in the state, says its rate of drug-affected births is about 1.2 percent. With 7,800 births at Swedish a year, that means Swedish alone sees more than 90 affected infants annually.

Nationally, the U.S. Office of Applied Statistics reported in 2005 that the national rate of drug and alcohol dependence is 9.25 percent, while Washington's is a tick higher at nearly 10 percent.

Underlying the problem of drug-affected newborns is the lack of access to drug treatment for pregnant mothers, particularly poor ones. A DSHS study in 1994 showed that only 21 percent of poor households in King County that needed substance abuse treatment and qualified for state-funded treatment got it, a figure on par with the state average. *C.T.*

legislators seeking to cut PICC's funding and moves by DSHS to lump PICC's budget in with its own. One year, he collected written testimony from PICC and University of Washington doctors to prove that the babies at PICC would have needed more expensive hospital detox had they not been sent to the center.

"It's been a battle to keep the funding in place," Upthegrove says. "It's frustrating to explain over and over that it saves money." Since the new state hospital guidelines were issued, PICC has clashed with DSHS over the impact of the guidelines and over decisions to send drug-affected babies home, sometimes against doctors' advice.

Ross Dawson, who, until recently, was head of program and practice improvement for DSHS's Children's Administration, responds that the agency can't always comply with doctors' recommendations. Babies can't be sent to PICC without either rarely obtainable parental consent or enough evidence of abuse or neglect to get a court order removing the child from the home.

In general, Dawson says, "We think kids are better off in families that can care for them than in institutions."

PICC staff members are very familiar with this argument, but don't always think it serves the children best. "Part of the issue," says PICC medical director Gaunt, "is that society as a whole somehow feels the natural course of events is babies should be staying with their biological parents, no matter what the circumstances. And that's unfortunate for the babies. Sometimes it's a little frustrating."

Dawson counters by pointing out that when home isn't a safe option, DSHS has specially trained foster homes where such infants can be placed. Many of the babies sent home or to foster care are then seen on an outpatient basis at other state-funded intervention programs, such as Safe Babies, Safe Mothers. He agrees the new policy creates a gap in identifying drug-affected babies whose symptoms may be slow to surface. But he says that gap stems from the federal law, to which the state guidelines must adhere.

And he denies any resentment on the part of DSHS toward PICC. "We see them as a valued and important partner and have a good relationship," he says. "Not every baby impacted [by drugs] needs this kind of 24-hour medical service, but it's an important part of the continuum. Some cases are managed quite well by ongoing medical care with a nurse or pediatrician educating the family how to care for the child."

Asked about DSHS, Drennen chooses her words carefully. "I think we have an excellent working relationship with *(continued on page 222)*

Spring Awakening

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Tender Mercies

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DSHS at the street level," she says. "At the top level, they are restricted by rules and regulations, and that's what we're working on. Everyone wants to help the babies, and we need to learn how."

WHILE SHE IS EFFECTIVE in Olympia, Drennen is truly in her element at PICC, where she focuses on her life's work—helping babies. When word of a new arrival comes, Drennen—who held a foster-care license for 43 years—hurries over to the soft-white receiving room where all newcomers are assessed.

A chubby-cheeked, 2-day-old girl, Erin, arrives via one of PICC's two vans, brought by a volunteer driver. She comes with a case file that includes a photo of a small boy holding her and giving her a kiss—a poignant reminder of absent family. Erin is withdrawing from meth and views her new caretakers with large, dark, sleepy eyes.

Drennen holds her, pronounces her "just darling," then snaps a photo. "Hopefully," she says, "this will give her a history."

PICC runs with the precision of a battleship. At 7 a.m. and 3 p.m., Drennen meets with the nurses, aides and other staff—whoever's on duty on that shift out of PICC's 60-plus staff members—to discuss each baby's status. Some are medically fragile, so it's important that everyone is up to date on their condition. Each child's progress is carefully charted on a large whiteboard. The babies' level of discomfort is graphed on an assessment sheet at regular intervals, to see if their medication needs adjustment to keep them comfortable.

More than 150 volunteer baby-holders take shifts at PICC, filling the rocking chairs and adding to the homelike atmosphere of the nursery rooms. The human touch helps the babies thrive, Drennen says. For extra-jittery or irritated babies, a dimly lit, low-stimulus room in the center of the ward helps them cope.

Building security is a top concern due to three factors: the presence of babies who are wards of the state, the presence of opiates and sometimes, the presence of their birth moms or other relatives, who can visit and learn about caring for their babies—if they follow the center's rules.

"They can't be confrontational or using," says nurse Denheyer. "The police are one block away, and we've had to call them."

Some babies stay at PICC for just a couple of weeks; some are there for as long as a couple of months. Last year, 54 percent of PICC's babies went home with a parent or relative, while 46 percent went to foster homes. Many are eventually adopted.

A set of premature, cocaine-addicted twins brought Brian and Jen Clintworth to PICC in 2004. The Black Diamond couple were on a waiting list to adopt and had said they were interested in a family group and open to biracial children. Weighing less than 4 pounds each at birth, petite Hannah and blue-eyed Caleb were exactly what they'd been searching for. They adopted the twins in 2005.

"There were no obvious signs of drug exposure," Jen recalls. "We were struck with how precious and beautiful they were. It was my heart's desire to have twins, from childhood, so it was a no-brainer for me."

Jen Clintworth says the couple spent many hours training with PICC staff to learn how to care for the twins. They learned to wrap them tightly in blankets to help them relax, and not to talk or interact with them while feeding, to allow the twins to concentrate on eating. They created a quiet, dimly lit home environment, in which the twins arrived at about 1 month old.

Once home, the Clintworths relied on PICC's offer of 24-hour support, calling when they had questions with issues such as Hannah's gastrointestinal reflux, a side effect of prematurity.

"They are the best resource in the entire world when you adopt a baby that has prenatal exposure to drugs," Jen says. "You can call in the middle of the night and say, 'I don't know what to do.' "

Since then, the twins have grown to be gorgeous, rambunctious 3-year-olds. Jen says all their tests have shown both children are on track developmentally.

Drennen has seen the Clintworth twins, and many other children over the years, who come back to visit after they leave PICC. She loves to see how well they're doing. She says that with proper care, most show no long-term effects from their prenatal drug exposure. Her heart breaks for the ones who slip through the cracks, for lack of funding or just tangled red tape, and don't receive the intensive treatment they might need to thrive. Those who receive early intervention will thrive, she says.

"When they leave us," she says, "the majority just fly." S