

Lifelong safeguards eyed for kids in need

Bill targets Fetal alcohol disorders

By Bonnie Miller Rubin Tribune staff reporter

Janis Groner's daughter is only 13, but Groner already worries about what will happen five years from now, when her child is no longer a minor. For any parent, the transition of a child to adulthood is frightening, but Groner's daughter has fetal alcohol syndrome, and though she may not show obvious signs of a disability, she has cognitive deficits with potentially lifelong implications. "We've worked so hard to teach her skills and to keep her safe," said the Wheaton mother, who adopted her daughter from the state when the girl was 10 months old. "I'd sure hate to see all those efforts go down the drain." That's why Groner and other parents of kids with fetal alcohol syndrome and related disorders are drumming up support for state legislation that would give them the same opportunity for guardianship as parents of children with cerebral palsy, autism and other developmental disabilities.

Currently, when adolescents with fetal alcohol disorders turn 18, they are subject to the same laws as any other young adult. Experts say that's unreasonable for a population that operates, on average, at a level two thirds of its chronological age, or roughly the level of a 12 year old at age 18. "Children who have been affected by exposure to alcohol during pregnancy . . . don't see that their actions have consequences," said Dr. Ira Chasnoff, a pediatrician at the Children's Research Triangle in Chicago, which evaluates and treats special need children. "They often don't look different than other children and usually have normal IQs, so schools, parents and others have unrealistic expectations, which only sets the children up for failure.

Both the House and Senate have passed the legislation. If the bill is signed into law, it would be the first amendment to this section of the state's probate law since 1979. The bills' chief sponsor, state Senator Don Harmon (D - Oak Park) became interested in the issue after hearing heartbreaking stories from parents whose children were approaching or had passed this milestone birthday. "This is not a marquee disease or a condition," Harmon said. "it exits in the shadows and seems to have a much broader impact than I realized."

Some 40,000 children are born in the U.S. each year with fetal alcohol spectrum disorder, or FASD, more than spina bifida, Down syndrome and muscular dystrophy combined. This disorders disproportionately affect adopted children, particularly those from Russian and Eastern European notations where alcoholism is rampant, experts say International adoptions started growing in record numbers in the late 1980's and those children are now nearing adulthood.

Fetal alcohol disorders occur when alcohol drunk by a pregnant woman passes through the placenta to the fetus. Prenatal exposure to alcohol can affect the part of the brain that controls decision-making and the ability to see cause and effect, putting youths at risk for a wide array of poor outcomes. A 1996 study by the University of Washington found that among adults with alcohol related neurological disorders, 50 percent had employment issues, 60 percent had trouble with the law, and only 18 percent were able to live independently.

With the right support from family, clinicians, therapeutic schools, medicine and mentors, many children with FASD do well. But once they turn 18 they can refuse such assistance.

The Illinois bill would offer parents the option of guardianship, a legal term giving a person authority to care for the personal and financial interests of another person, called a ward, if a judge determines that person cannot make sound decisions. Guardianship would allow parents to help manage the health and finances of their adult child - to step in, for example, if the child runs up credit card debt or falls for in Internet scam. There is no time limit on guardianship, and severing the guardian's authority requires a court hearing. "You have the stability of being in a continuing parent-child relationship, even though the individual has reaches the age of majority," said Brooke Whitted, a Northbrook-based attorney. The arrangement cannot keep someone from signing himself out of a hospital, Whitted said. The guardian cannot be held personally liable for the ward's debts or actions.

Bonnie Buxton understands the bumpy transition period well. Her oldest daughter, adopted as a toddler and now 27, lived on the streets of Toronto for a while and had two children by the time she was 19. Though her daughter is now starting junior college, Buxton knows the need for supervision is not going away. "They are minors lifelong," said Buxton who wrote about her experience in a book titled "Damaged Angels." As an advocate, Buxton said she fields at least two calls a week from parents of young adults who are shocked to find they have no say when their children encounter financial or legal difficulties.

"These kids end up at the wrong place at the wrong time with the wrong people, and parents have no control." She said. "Once they hit the magic 18, to the court system they are just another loser." With the help of a classroom aide, Groner's daughter is on the 7th-grade honor roll. But if the bill does not pass, Groner said she will eventually be shut out of the process of helping her daughter succeed. "That just doesn't make any sense," Groner said. "We need to close this loophole, so we can protect the past and invest in the future."

Fetal alcohol syndrome by the numbers

40,000

Children born in the U.S. each year with a birth defect from alcohol use during pregnancy.

\$1 million to \$5 million

Estimated societal cost per child, including lost productivity and incarceration.

0

Amount of alcohol that experts say can be safely consumed during pregnancy.

47.5 percent

Women surveyed in Illinois who said they drank alcohol in the **three months before** becoming pregnant.

6 percent

Women surveyed in Illinois who said they drank alcohol in the **last three months** of pregnancy.

BEHAVIORS LINKED TO FETAL ALCOHOL SYNDROME

- Sexually acting out
- Poor judgment
- Memory deficits
- Poor impulse control
- Trouble with the law

Source: Illinois FASD Task Force
Chicago Tribune