

Failure to protect

St. Louis Post Dispatch

Friday, Sep. 07 2007

Last week, the Missouri Department of Mental Health released a 100-page federal inspection report that was severely critical of the state agency's management of Bellefontaine Habilitation Center in north St. Louis County. Federal inspectors, who conducted their on-site investigation in June and July, said that conditions at Bellefontaine posed "immediate jeopardy to resident health and safety."

They cited the failure of Bellefontaine staff to restrain a severely mentally disabled resident who was injuring herself repeatedly. They found fire safety violations in the center's main buildings and in each of the 23 "cottages" that function as group homes.

They also cited the DMH for violating provisions of federal law that require keeping medical records private.

As it turns out, the DMH's release of the federal report last week also inadvertently violated that medical privacy law, the Health Insurance Portability and Accountability Act of 1996 or HIPAA. The report — which the state sent to the Post-Dispatch and other news organizations, several state legislators and some families of residents — included information that allows 27 patients to be readily identified by name and medical condition.

The release of resident names is "totally inappropriate," DMH Director Keith Schafer told the Post-Dispatch on Wednesday. "You should not be receiving a list of patients' names and their level of functional disability," Mr. Schafer said. "This is totally unacceptable."

What also is unacceptable is the continuing failure of the state — despite years of warnings, reports and investigations — to protect and care for the desperately vulnerable people who are its responsibility. The federal inspection of Bellefontaine was completed in July. That came after the August 2004 death of resident George Holmes, who complained to a relative during his final hours that he had been beaten; after the 2006 deaths of two patients at another St. Louis area habilitation center; after a Post-Dispatch investigation last year that documented 21 deaths and hundreds of injuries from abuse and neglect; and after a U.S. Department of Justice investigation earlier this year.

Along with the federal report, the state also released its plan for correcting the documented problems. As an-



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2007–2008 LEGISLATIVE PRIORITIES

- Minority status for workshops
- Habilitation centers
- State Schools
- Medicaid waiver slots—more need to be opened
- Dental health services
- DMH Leadership
- Case management guidelines
- Prioritization of need guidelines

nounced by Mr. Schafer last week, the state intends to have private contractors take responsibility for the care of most Bellefontaine residents. Eventually, they will be moved into small group homes around the region.

Although the shift to smaller group homes is good in principle, in practice it makes the job of ensuring their safety even more difficult. It is difficult to see how a state agency that has been unable to protect residents at its own habilitation centers will be able to exercise the oversight required to keep tabs on facilities run by private companies.

In some other states, the U.S. Justice Department has filed suit to protect residents in state institutions, and some federal judges have stepped in and ordered changes. Neither has happened yet in Missouri.

"You can say [to workers] that these are the rules, now follow them, but that doesn't do it," Mr. Schafer said this week about the department's repeated failures. "You can say 'I'll punish you if you don't follow the rules.' That doesn't do it either. You have to get people to believe [that following the rules] is really important. That's where we're still struggling," he said.

Meanwhile, residents remain at risk.

IN IRELAND

SMURFIT KAPPA UNDER INVESTIGATION

Investigators are looking into claims that thousands of disabled and mentally handicapped people are underpaid or not paid at all for working at charities and businesses, including Smurfit Kappa Group, reports IrishAbroad.com

Among these claims are programs in which disabled people work for what are called sheltered workshops, where they carry out light tasks as part of their therapy for charities and hospitals.

The Equality Authority, which investigates discrimination in the workplace, is looking at Peamount Hospital, near Dublin, which pays workers less than \$18 a week to make boxes for Smurfit Kappa.

Smurfit Kappa said that it did not know how much the workers were being paid and that it had been approached by Peamount Hospital.

“The fact that people with intellectual disabilities receive as little as \$18 a week in some training centers is a remnant of a severely outdated system that should have no place in modern society,” says Michael Ringrose, head of advocacy group People with Disabilities in Ireland. “A clear divide needs to be struck between what constitutes employment and what is genuinely therapeutic activity.”

Killer Appeals His Third Death Sentence

At issue now is whether condemned man is mentally retarded

By Virginia Young
Post-Dispatch
Jefferson City Bureau Chief

Jefferson City—Twice the Missouri Supreme Court has thrown out the death sentence of Ernest Johnson, who killed three people in Columbia, MO., with a hammer.

On Wednesday, his lawyer asked the court for a third reprieve, on grounds that Johnson is mentally retarded. The state disagreed with that assessment. The case could set the standard for how mental retardation is determined in death penalty cases.

Johnson was convicted in Boone County Circuit Court of bludgeoning to death three convenience store employees on Feb. 12, 1994.

The high court overturned the death sentence in 1998, saying Johnson had an ineffective lawyer. The court threw out Johnson's second death sentence in 2003 because his attorney did not present adequate evidence that he might be mentally retarded.

The court relied on a U.S. Supreme Court ruling known as Atkins vs. Virginia. In that 2002 decision, the court held that executing the mentally retarded is unconstitutional. But the court let state legislatures define mental retardation.

Under Missouri law, before criminals can be considered retarded, they must have “significantly sub-average intellectual functioning” with limitations in two “adaptive behaviors” such as social skills, home living, health and safety. The conditions must be documented before age 18.

Wednesday's arguments in the Supreme Court centered on whether Johnson fit those criteria and how far the state must go to disprove such a theory.

Johnson's attorney said that a 2003 test put Johnson's IQ at 67, and that anything below 70 was considered sub-average. The state countered that Johnson's diagnosis depended on anecdotal evidence gathered from his siblings and from others with questionable credibility.

Assistant Attorney General Evan Buchheim noted that no psychologist or psychiatrist found that Johnson was mentally retarded until his third penalty-phase proceeding began. By then Johnson was older than 40.

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The IQ of Children With Autism

(letter in Newsweek, September 10, 2007)

I wanted to thank you for “The Puzzle of Hidden Ability” (Aug. 27), about the IQ of autistic children. My child was found to have a very low IQ. At the time he was tested, I was told that he must have scored so low because of his inability to connect with the instructor and that he was selectively nonverbal. I have wanted to get him tested again because he has become more verbal and has better social interactions, but just as your article stated, he may not get some of the services that he currently receives if his IQ falls in the “normal” range. As parents, we fight to get our children what they need to be successful and healthy. I cannot justify having services taken away that I struggled to get.

Diane Lane
Grasonville, MD.

Perseverance is a great element of success; if you only knock long enough and loud enough at the gate you are sure to wake up somebody.

Henry Wadsworth Longfellow

JUSTICES DEADLOCK ON SPECIAL EDUCATION CASE

By David B. Caruso
The Associated Press

New York—A multimillionaire who sued New York City over its refusal to pay for a private school education for his learning-disabled son won by default Wednesday when the Supreme Court couldn't agree which side was right.

The justices split 4-4, leaving intact a lower court's ruling in favor of former Viacom and MTV executive Tom Freston.

The potential tiebreaker, Justice Anthony Kennedy, did not participate in the case.

On its face, the outcome means that New York City's Education Department will have to pay Freston a little less than \$22,000 to cover a year's tuition at the private school in Manhattan his son attended after he was found in the late 1990s to have mild learning disabilities.

But the court didn't address the case's key question: Do the parents of special education students have a right to demand a private school education for their kids without giving public schools a try first?

The 2nd U.S. Circuit Court of Appeals held that parents who can prove that their child couldn't get an appropriate education in the public schools may sue for private-school tuition reimbursement even if they had never tried the public system.

New York City officials had agreed that some students do need private placements, but argued that federal law barred payments to pupils who did not enroll in public schools for a least a brief period of time.

The city initially paid \$50,000 in tuition over two years for Freston's son at the private Stephen Gaynor School, before deciding to stop the payments and insist that the boy attend a city-run program, prompting Freston's legal challenge.

Nationwide, the number of special education students placed in private schools at public expense has risen to 71,082 in 2005 from about 52,012 pupils in 1996, according to the U.S. Department of Education.

In Illinois, public school districts usually are able to provide the necessary services. But when a student requires additional services, the district will send him or her to a private school. The district is then reimbursed by the state.

In Missouri, individual school districts are responsible for reimbursing parents for special private education.

"Local districts only pay if a parent is able to show that the district cannot offer an appropriate program," said Heidi Atkins Lieberman, the assistant commissioner for the division of special education for the Missouri Department of Elementary and Secondary Education.

She said the burden of proof was on parents to prove that special education programs offered by public school districts were not appropriate.

When normal rules don't apply

Lucy Mangan
Saturday, October 20, 2007
Guardian

I hope that by the time you read this, Alison Thorpe's 15-year-old daughter Katie will be on her way to being granted the hysterectomy her mother wants her to have. Katie has severe cerebral palsy and a mental age of three months and her mother wants her to avoid the discomfort and confusion menstruation would bring. The case is currently in the hands of NHS lawyers, who will weigh up the benefits to Katie against the potential damage to human and reproductive rights among disabled people.

Several years ago, I was pretty well immersed in what you might call "the disabled world". I spent half my week working as a volunteer at a disabled school, and I was going out with the father (Dave) of one of the children (Paul). I learned a lot in the way of wheelchair and catheter-based practicalities, but what remains is the knowledge that unless you have witnessed the ramifications of severe disability day in, day out, you cannot appreciate how inapplicable normal standards, normal judgments, normal social niceties are and how compelling the need for new definitions of them becomes.

For example, feeding a child with cerebral palsy is more akin to wrestling than spooning gloop into a baby. To feed Paul, you pinned down his arms with one hand while with the other you poked bits of food between his wildly gnashing molars. Then you held his head in a vice-like grip so he could concentrate on chewing and swallowing without choking. And if his tongue-thrusting pushed half-masticated food out, you pushed it right back in again, because that disgusting gooey mess was a hard-won achievement and neither of you wanted it wasted. If this all took place in a cafe on a day out, people would look horrified and, occasionally, come over to remonstrate. And because Paul couldn't speak, you had to assure the do-gooder that Paul wanted to have his arms held down - it allowed him to concentrate on opening his mouth - and that the "unhygienic" finger-poking was preferable to him lacerating his mouth on a spoon, and - oh, and just piss off, you ignorant, interfering cretin who is ruining what small

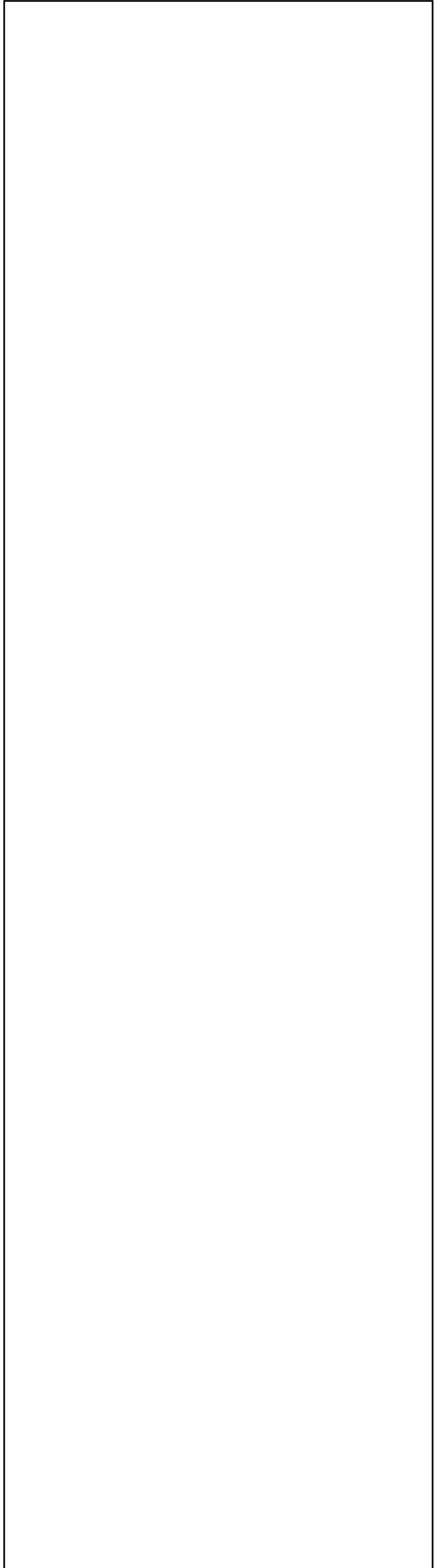
pleasure Paul can take in lunchtime.

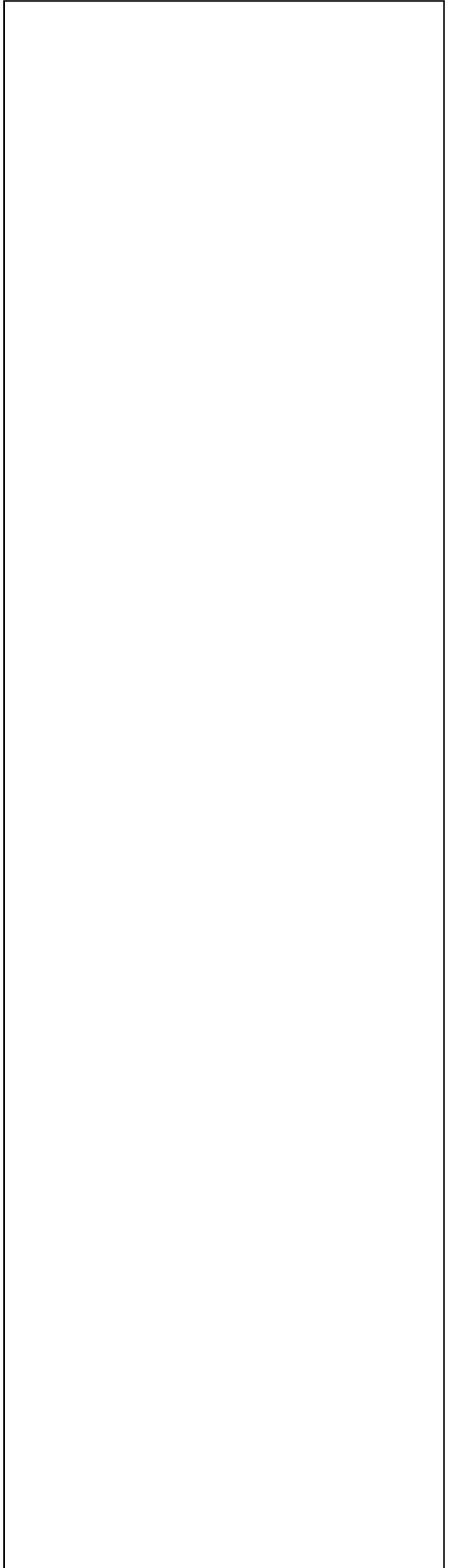
Children stare, they come up, they ask questions. That's fine. Adults dart embarrassed, furtive, frequently filthy looks. I never decided how much of the hostility was due to our temerity in taking out in public this upsettingly flailing child and how much was due to their assumption that Dave, who was also mildly disabled, and I were deliberately breeding the things. The lack of manners, common sense, basic compassion, let alone empathy used to drive me to distraction.

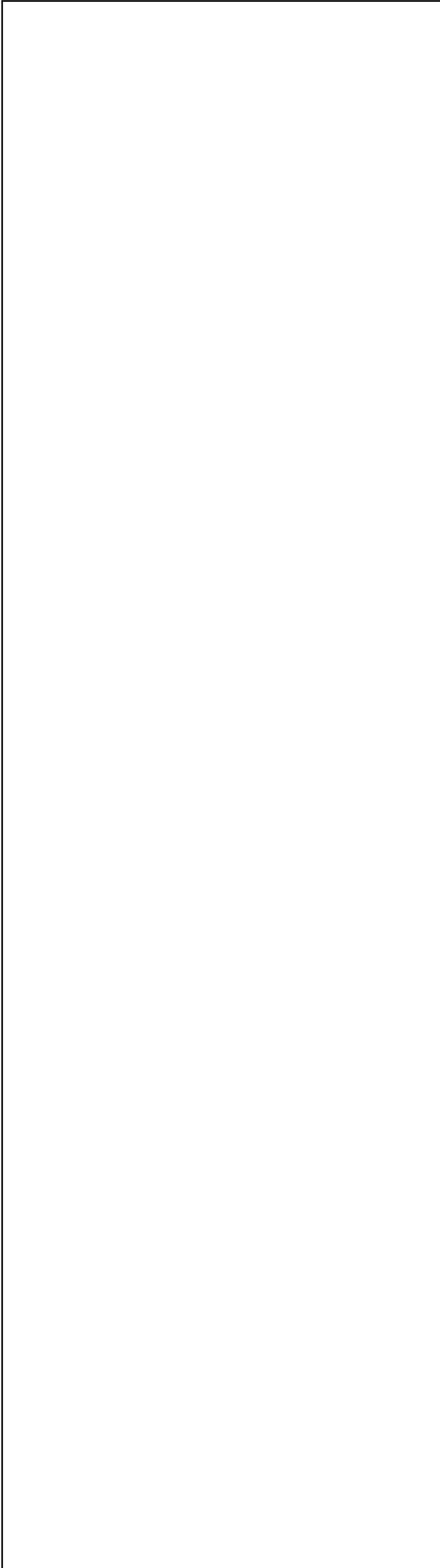
Such reactions are what underlie any contention that a hysterectomy for Katie Thorpe is wrong. To save a doubly-incontinent child (who will remain mentally a child for ever) the strain of periods and an additional round of strippings and changings in her life requires an imaginative leap to a different definition of human rights from the one for the able-bodied. Protecting a severely disabled female's reproductive rights requires prioritising her right not to have a baby over the usual right to procreate, especially when, if she outlives her devoted parents, the truth is that she will always be in greater need of protection from abuse than her "normal" counterparts.

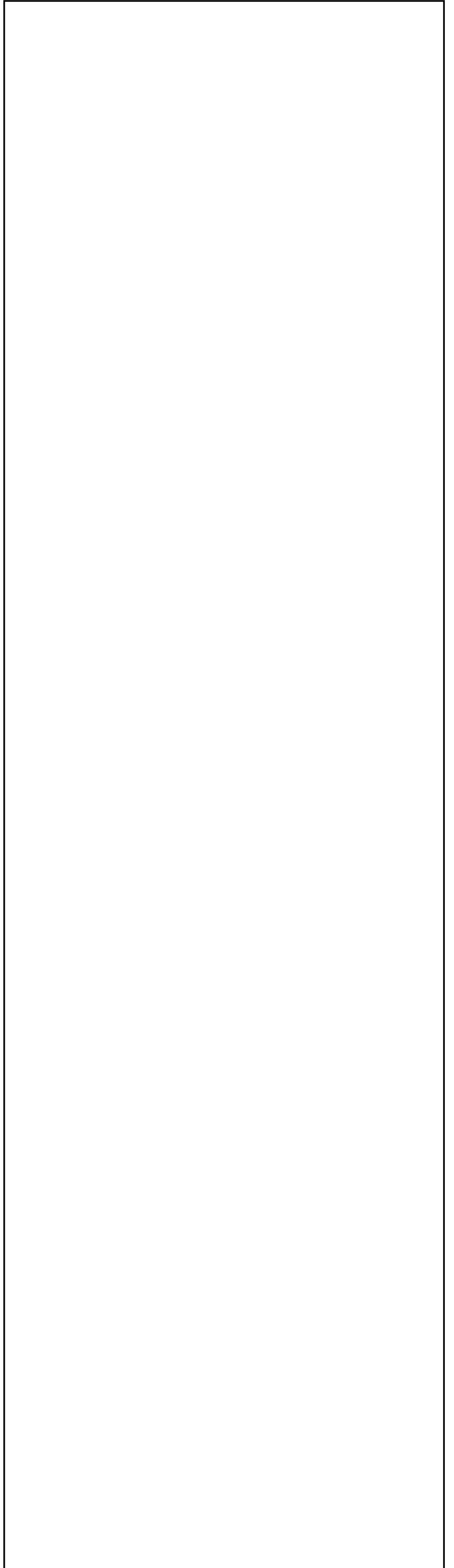
Alison Thorpe is seeking to disapply the normal rules because her daughter is in an abnormal situation. Like giving lunch to Paul in the cafe, the operation might look to the ignorant like an assault, in fact it is anything but.

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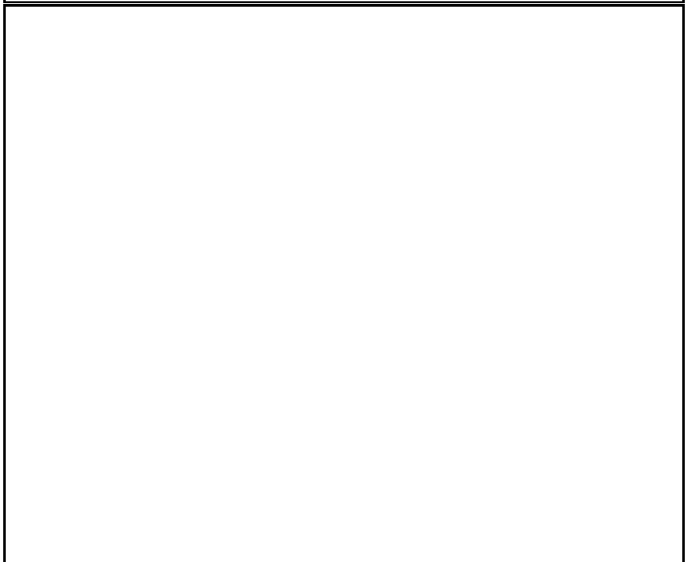
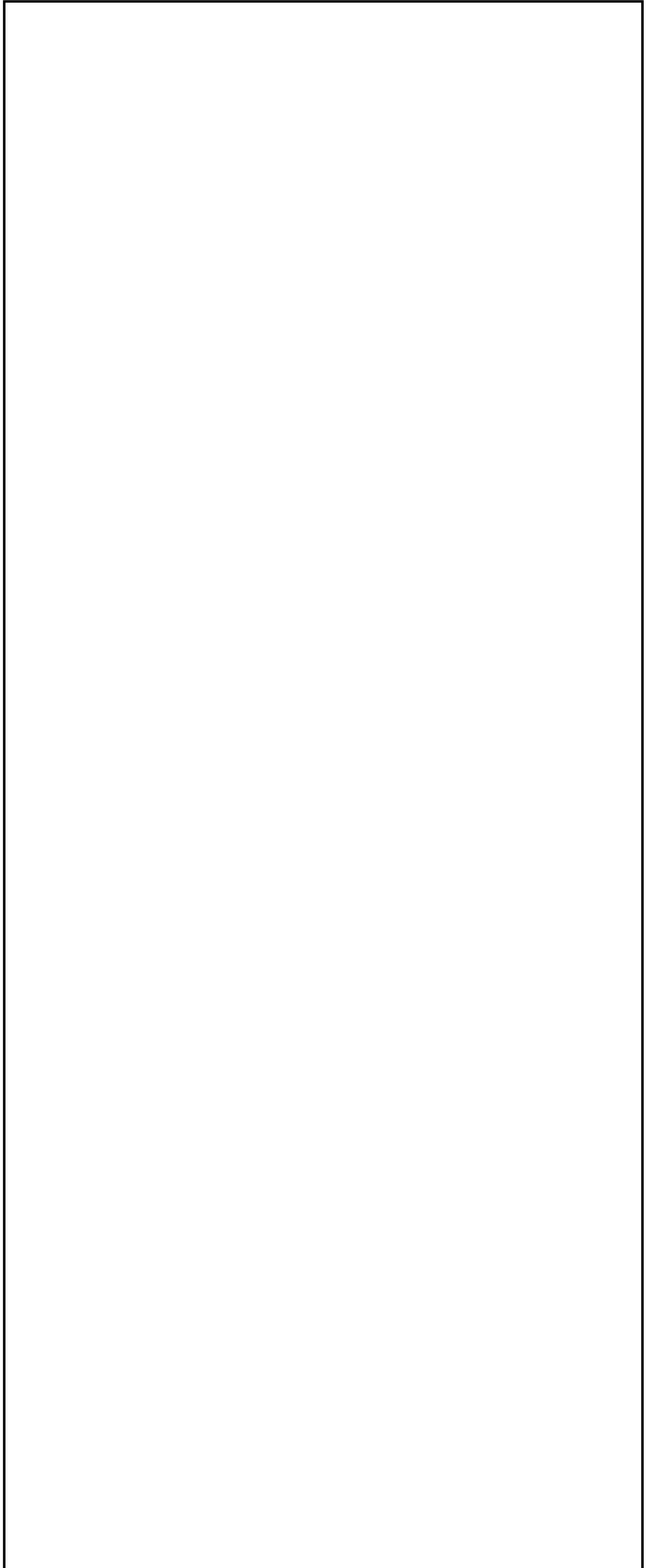


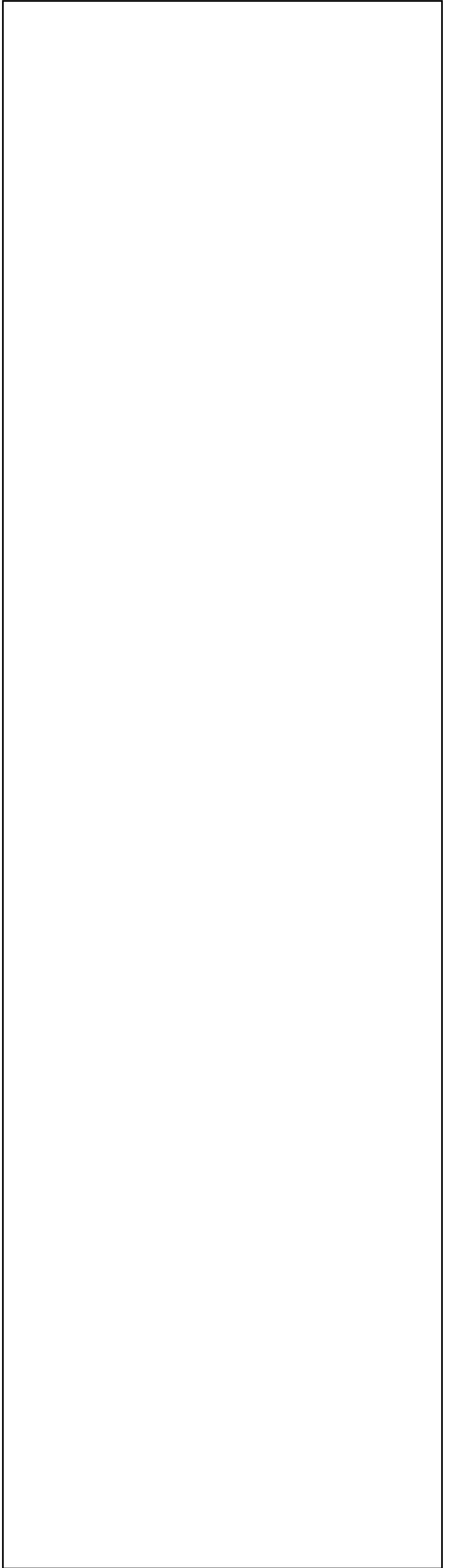


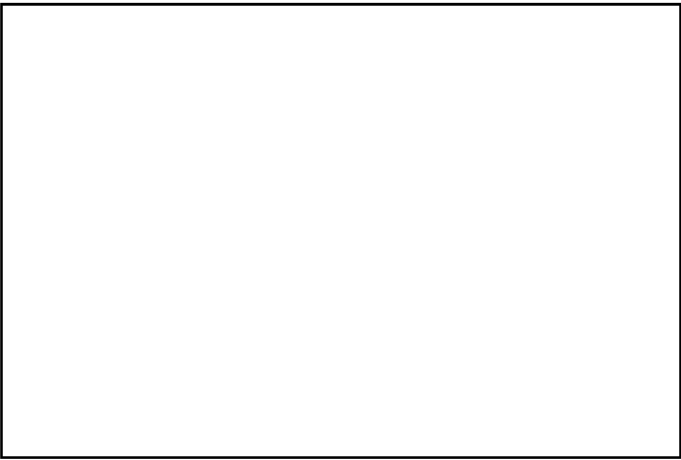




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