

Maggie Hoffman
Hampden
LD 2009
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To the chairpeople and members of the Health & Human Services Committee:

I am writing AGAINST LD 2009, as a parent and guardian of my 36 year old son Jake. Jake lives with multiple disabilities, acquired through his extreme premature birth and consequent brain hemorrhages. Against all odds, and despite the predictions of the neonatal physicians caring for him throughout his 4.5 month NICU stay, Jake survived. It was instructive for me and Jake's Dad to learn that acute care medical providers can be amazing life-savers and yet be completely uninformed about life itself and the options for day-to-day care outside of a hospital.

Jake was at the leading edge of an epidemic of children who survived because of better technology and medical care, but need life-long and sometimes extraordinary support and care.

Jake's neuromuscular challenges (feeding, balance, walking), intellectual disability (learning, safety, self-care), autism (communication, sensitivities to change, sound, light, other people), medical conditions (seizures, pain) challenged all of us for years to develop good strategies and develop accommodations to support him at home, school and in our communities.

Unfortunately, Jake's depression and anxiety gave way to severe psychosis during his teen years. Suddenly elopement, violence towards himself & others, and suicidality, resulted in a traumatizing visit to a psychiatric ER and then an inpatient stay followed. We kept being called by the hospital, "Would you bring food for Jake, we don't have a way to feed him safely", "Give us permission to put a bed in the supply closet, Jake is non-self-preserving and we can't keep him safe from the other patients", and then, "We no longer have a unit for teens with intellectual and developmental disabilities and don't know what to do with him, you need to pick him up."

We were trying to change the physical environment at home to keep him and the rest of our family safer; we didn't have any support staff set to help, and the outpatient psychiatrist didn't have a medication plan. Yes, I was a lot younger then and could absorb the aggression. It would be dramatically harder now to take him home without a comprehensive plan in place. Our family neither wants nor expects a different setting for him, just a realistic plan for support staff, useful strategies as well as the willingness to try to identify a more effective and well tolerated medication plan.

Importantly, given all of Jake's unique support needs, how could it possibly be in anyone's best interest to have Adult Protection Services in the mix during the grimmest of times?? How would Jake or anyone be better served with our existing legal guardianship severed just because a hospital couldn't/ wouldn't provide care until a well-resourced home and community service plan can be developed and put in place?

I urge you to vote down LD 2009.

With appreciation for all you do.
Maggie Hoffman