Achieving Better Outcomes for Hawaii’s Children

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Act 333, adopted by the State Legislature in 1997, notes that traumatic brain injury is the leading cause of death and disability in children and young adults. While Act 333 requires the Department of Health to develop a comprehensive plan to address the needs of persons affected by disorders resulting from such injuries, it is clear other more preventative measures must be taken to deal with this problem.

These are trying times for Hawaii’s families. The lingering economic slump and predominance of low-paying service sector jobs, unemployment figures on the rise, and the high cost of living continue to test our resiliency. Providing the kind of care and attention children need to thrive is particularly challenging under such stressful circumstances. Indeed, recent reports of infant deaths and traumatic brain injuries resulting from child abuse have many concerned that a growing number of families may not be coping well at all, and that despite a shrinking state budget, somehow we must do more to help children at risk.

Act 333, adopted by the State Legislature in 1997, notes that traumatic brain injury is the leading cause of death and disability in children and young adults. While Act 333 requires the Department of Health to develop a comprehensive plan to address the needs of persons affected by disorders resulting from such injuries, it is clear that this issue calls for additional preventative measures to deal with this problem.

The need to be proactive about child safety becomes even more urgent in light of recent discoveries about the significance of early brain development. In the last several years, research findings have underscored the fact that more learning and growth take place in the first two years than at any other time of life. Recent studies, such as the one released by the Rand Corporation, reinforce what we have intuitively realized all along - that the kinds of experiences that infants and toddlers are exposed to have a lasting impact. Quality care and nurturing will pave the way for a lifetime of successful learning. Conversely, prolonged exposure to severe stress can actually change the physiological development of a child’s brain leading to learning handicaps and other developmental delays.

In Hawaii we pride ourselves on how the state’s public policy reflects our love of children. We do not want to sacrifice the gains we have made on their behalf, despite the gloomy financial news. With this in mind, a coalition of community leaders, state legislators, and public and private agency representatives have been grappling with ways to make the most of existing resources. In the face of shrinking human service budgets, we must develop innovative approaches which will help shift cost from expensive intervention and treatment services to more economical prevention programs that have a positive impact on child outcomes.

During this past legislative session, lawmakers and the Cayetano Administration acted on several measures that will bring people together to take collective action on important child outcomes. In particular, House Concurrent Resolution 38 establishes a state policy and a recommended course of action for improving the well being of children, youth and families.

The document draws from a number of statewide initiatives to define a continuum of good outcomes for children from the time of birth through young adulthood. For example, “Every child will thrive physically - be healthy from birth with ongoing access to good health care, have a safe home, school, and community environment” is generally accepted to be a fundamental requirement for all children to thrive. It acknowledges that “the majority of children and youth are mentally and physically healthy because they grow up in loving sustaining families where the care of children is viewed as a fundamental responsibility, however, all families need supportive communities and some families need more support than others to assure good outcomes for their children.”

Providing appropriate support to enable communities and families achieve these outcomes will take a more focused approach than in the past, and the resolution prescribes a means to do so. It calls for communities and public and private services providers to think strategically about ways they can combine resources and energies to address common goals. It also calls for the development of a mechanism to measure progress on achieving the desired results for families over time and for government as well as private, non-profit agencies to cooperate on gathering and sharing data that will make this possible. Thus, the resolution helps set the stage for the creation of “performance partnerships” for the state.

The Office of the Governor is very committed to the concept of performance partnerships, an idea that is being promoted by the federal government, through the National Performance Review Board and Vice President Al Gore’s Office. The National Performance Review Board is currently developing mutually beneficial agreements with a number of leading states in order to pursue key outcomes that are important to those states and federal government.

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enhanced. This is particularly true of patients with TBI, who can be especially outrageous in the demands which they make of their health care providers. (E.g., patients with TBI often seem not to comprehend or accept the treatment rationales provided by their doctors for particular medical regimens to which they rigidly and persistently object, or vacillate in their decision-making, resulting in problematic patient management.)

Finally, opportune involvement of a neuropsychologist can prevent the development of psychiatric conditions which can be expected to needlessly hinder the clinical progress of the TBI patient. For example, survivors of TBI who are at risk for manifesting comorbid anxiety or depressive disorders can be properly identified and provided with early psychological intervention. In a similar manner, TBI patients with complaints of cervical pain or headache may receive appropriate psychological attention so as to reduce the chances of their symptoms escalating to a full-blown chronic pain syndrome. Patients afforded timely and appropriate psychological intervention may also be more likely to avoid further physical injury or aggravation of their medical condition.

Conclusion

Traumatic brain injury does not have to be the “silent epidemic” that it has been. Survivors of TBI no longer need to experience their residual loss of cognitive function as a phantom in their lives—invalidating their impairment as well as stealing their dignity and self-respect. An already difficult process of grieving their functional losses and accommodating their medical condition does not need to be exacerbated by denying that a bonafide disorder exists. Survivors of TBI should not have to “go crazy” trying to prove that something is wrong with them. They should not be made to feel that they are “making a big deal out of nothing”—manufacturing or exaggerating their functional problems when no basis for them exists. Patients with TBI should not be stigmatized with the insinuation that they are faking their difficulties or otherwise malingering.

Clearly, when patients with TBI are responded to in this way by health care professionals, progress in treatment is likely to be hindered. TBI patients—like patients with any medical disorder—are prone to become even more preoccupied and invested in their impairments, when their clinical symptomatology is challenged. The predictable outcome is that everyone loses: patients with TBI are likely to persist in their symptoms, for treatment is not likely to be forthcoming for those not even perceived as having a valid medical disorder. The attending physician is likely to be left with a difficult and uncooperative patient on his/her hands. The patient’s family is stuck with a family member who is likely to become increasingly hard to live with. And society loses a once productive citizen, whose impairment might very well have been successfully remediated, to the extent of being returned to substantial gainful employment.

In conclusion, a favorable prognosis is more probable if the patient with TBI is recognized early on, ideally beginning with the attending physician, in consultation as necessary with a specialist in neuropsychology. Timely and appropriate neuropsychological assessment can confirm the TBI diagnosis, yield reliable identification of cognitive deficits, and give rise to suitable neurotraining strategies targeting the specific damaged brain functions of the TBI patient. The subsequent clinical course for the patient with TBI is thereby more likely to lead to a positive therapeutic outcome.

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In exchange for making a commitment to work on outcomes and measuring progress over time, NPR will negotiate with appropriate federal agencies to permit more flexible use of funds at the state level through less restrictive regulations. This helps states make the most of federal dollars by allowing spending outside of narrowly defined categories. State agencies, working hand in hand with communities, are encouraged to disperse federal funds so that they can address specific local needs, priorities and support tailor-made solutions to community problems.

The National Performance Review Board is impressed with the broad-based efforts in Hawaii to define important outcomes, particularly with respect to children. The Office of the Governor has been in discussions with Vice President Gore’s Office about formalizing an initial partnership agreement with NPR that will focus attention on early childhood outcomes. The Good Beginnings Alliance, a private, non-profit organization with statutory responsibility for coordinating improvements to the early childhood system, will play a major role in advancing the terms of this agreement. By working with public and private agencies as well as local Good Beginnings Councils, the Alliance and its partners will help organize a community-based response to ensuring that young children are safe and living in nurturing environments.

Thus, by achieving more clarity on the important goals we wish to achieve, mobilizing communities and providing greater incentives for collaboration towards achieving these goals, we see opportunities for making a difference in the lives of at-risk children. This three pronged approach gives us hope that maybe we indeed can do more with less.