



The Issue: Lack of funding sources for families who require a modified van to transport their children on a daily basis.

Having a child with a disability is riddled with challenges. Simple things take on new meaning that few can understand without living it. We learn to live with and even accept the daily struggles we wage – in the interest of creating a more meaningful and happy life for our children. The worst insult comes when even though we have accepted these struggles and carried on with heads held high – we then learn that we must not only engage in daily struggles and extreme efforts to ensure this meaningful life – but we must also fight for the tools necessary to do it, even after we have picked ourselves up and resolved to do what we need to do for our children.

You probably rely on having a car, most of us do. They are critical to rural living. What if you were bound by an agreement that every car you would ever have would be a Mercedes, and the starting price was 55,000, no matter what your income was, is, or will be. This is the reality of parents who require van modifications. We need to transport our children, and the vehicle requirements are often upwards of 50K. Add to that the daily needs that often require at least one parent working less than full time, and you can see where this leads. Hard working, dedicated parents who can't figure out how to purchase the car of the rich and famous – and are forced to resort to things like giving up what little precious family time they have in order to engage in enormous fundraising efforts, often swallowing pride to ask neighbors in their hometown to help them out. Regardless of the giving nature of these neighbors, it's difficult to swallow one's pride and be in this unavoidable situation.

OR sometimes, funding is available elsewhere, creatively using for example Personal Care Services funding through the C3 program – this program was available to very few people as a pilot project and has never opened itself up to more. Further, in order to use these funds, a family forfeits personal care time for their child, thereby increasing their own personal physical and emotional burden.

It's been my experience that families who have a child with special needs are some of the most hard working and dedicated people I know, regardless of the fact that they bear such a large burden. It seems unreasonable to not have a source of support so that citizens of Vermont, child or adult, can get out of their house and access education, work, and their communities. And – what cost do we bear when we leave families with no choice but to shoulder the burden of solving this problem on their own? What mental, physical, and financial price are they suffering, which likely results in a toll on the state system in other areas.

It is our hope that in the coming legislative sessions an answer to this problem of gap in coverage for a medically necessary piece of equipment will be solved, and we are actively gathering family stories to help inform this decision making process.

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