

## Concerned Parents

Hayden is a 9 year old boy, diagnosed on the DSM IV with Asperger's syndrome at the age of 4.

Hayden's journey with ASD has been one filled with challenges, successes and incredible learning, made possible by a tight circle of family, loved ones and professionals. His needs have changed every year from being non-verbal at 18 months, to repetitive and restricted play, insistence on sameness and routine and a lack of social interactions at age 2. When Hayden was 3 we saw challenges with transitions, noise and being in social situations with new people. When Hayden started school he was on a modified schedule with a lot of support to help him navigate the new environment. Every year his needs have changed, and I could never have predicted how far he's come or how many gains he's made. It's been a journey of ups and downs and the challenge with annualized funding, is that it's not responsive to his needs at any given point in time; it doesn't allow for more intensive service through puberty or navigating the employment world. We are faced with decisions on how to spend his childhood budget, but with ASD you cannot predict when the next crisis will hit or the new need arise. We might register him for a social group that fits with his needs of navigating the complex social world at school, but unbeknownst to us, 6 months later his ticks, anxiety and struggle with sleep could pop back up, when we have no funds remaining in our childhood budget to get him the prioritized supports he will desperately need.

Hayden is a little guy who does best with a team he knows and has built relationships with. By removing the funding to regional providers, he's at the mercy of whatever private service provider will sell us services that match his needs. The amount of money we will need to spend for him to pair with a new therapist and develop a relationship will leave us with precious little resources to actually buy the treatment. He also does best in group settings, but being from the North, the availability of similar aged/abled kids is hard to arrange at best, never mind now that parents will have to choose to spend their money on the same group we are trying to offer for Hayden.

*Concerned parents*