

# THE CO\$T OF INDEPENDENCE

*The need for housing options for adults on the spectrum is tremendous—and the price tags can be stunning. . .*

BY CATHERINE PURPLE CHERRY, AIA, LEED AP,  
CERTIFIED AUTISM SPECIALIST

I am the mother of a child on the autism spectrum and am also the sibling of a brother with Down syndrome. My son on the spectrum is currently 24 years old. As the principle of an architectural firm, I've spent my last decade serving special needs environments through my Purposeful Architecture studio of Purple Cherry Architects. For over 20 years, I've been a staunch advocate for programs for my son and for the children of others. I reside in the state of Maryland, and serve on the National Autism Society Board. I've had the great



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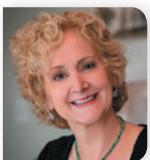
opportunity to visit many residential programs across the country as well as assist in the design of modular group homes and semi-independent living opportunities for our children. My son is considered high-functioning though he has other diagnoses that cohabitate with his autism. He lives in a group home in the community, is engaged to his girlfriend, and is employed full-time. He is state-funded for both day supported services and residential placement.

As an architect, I find that I have a strong visual and mathematical mind and also am very intuitive, skills



▲ **BEATLEMANIA**—Special needs architect Cathy Purple Cherry's son is a long time Paul McCartney fan.

## CATHY PURPLE CHERRY, AIA, LEED AP...



...Cathy is the principal of Purple Cherry Architects. Purposeful Architecture™, a studio within her firm, focuses on environmental design for children and adults with challenges. Cathy is personally connected to the special needs community by her life experiences with her son, who has autism. She provides a unique perspective, and has the ability to translate the needs and mission of an organization

into physical design. Visit Purple Cherry at [www.purposefularchitecture.com](http://www.purposefularchitecture.com)

that have come in handy when assisting multiple families in their own pursuit for programs. I've witnessed things done well and things not done well. The current major flaw in our system—aside from the fact that funding does not cross state lines—is the transition years between our educational programs served by the Department of Education and our adult services served by each state disability agency. What I find to be true about our kids is that too often people assume that they are not able to accomplish tasks. This assumption is frequently wrong. What I've observed over my lifetime of 56 years is that any child with challenges has the ability to learn. Helen Keller is an excellent case in point.

## DELAYED INDEPENDENCE

My specific focus for this article is for the high-functioning autism population. What is true for every transitioning young adult who moves into the age group of 21 or 22 depending upon the state, is that they will always qualify for some form of day-supported services. If these services are not being provided, it's likely more of a geographical issue than anything else. These day-supported services come in the form of transportation, vocational training, supported employment, job coaching, and simply daycare. Specifically, in the state of Maryland as likely exists in other states, the New Directions program allows for parents and their children to establish their own supports. Whether your funding comes through this type of program or directly through a service provider, the cost is usually upwards of \$30,000 per year for each adult on the autism spectrum.

What many people don't realize is that our high-functioning autism population has the ability to learn even though it may be at a delayed pace compared to peers. Throughout my son's childhood, I was able to recognize that consistency provided the opportunity for learning, that modification to the specific efforts allowed for success, that simplicity and repetitiveness provided less stress, and most importantly, that age allowed for a maturation similar to a neurotypical child—only ten years later.

So what does this mean for housing? For me, it's pretty simple. What is very accurate is that we do not have enough funds in any state to support all of our special needs children in residential models. What is also true is that our children are more often living at home and missing out on social opportunities until the age of 52 when their parents themselves become disabled or deceased. In order to increase opportunity for our more severely impacted populations, we have to support our high-functioning individuals to full independence. I fully believe that my son at the age of 24 is much more similar to a young teen at the age of 16. So what that means to me is that he needs a few more years to grow and mature. In my neurotypical son, I saw the greatest maturing between the ages of 15 and 19. I currently see a similar maturation in my high-functioning son. My son on the spectrum currently lives in a fully-funded home with three other adult individuals even higher functioning than him.

## DOLLARS & CENTS

So let's look at the financial picture of this proposal. I have assumed the transitioning age of 21. The majority of students transitioning receive day-supported employment supports. These supports typically average approximately \$30,000 per year per individual. If the average life expectancy of a child with high-functioning

autism is 78, then this child will live with day supports for 57 years. \$30,000 per year for 57 years is equivalent to a cost of \$1.71 million to support this individual during their day for their lifetime.

## THE COST OF INDEPENDENCE



**\$30,000**

At the age of 21 in most states, individuals on the autism spectrum transition out of educational programs and are eligible for day services. The approximate cost of these day services is \$30K.



**78 years**

The average life expectancy for an adult in the U.S. is 78 years.

Centers for Disease Control and Prevention

(CDC) estimates that about 1 in 68 children has been identified with autism spectrum disorder (ASD). Of those, approximately 50% have an average or above average IQ. Regardless, 81% of adults with autism live with their aging parents.

## Let's do some math!



**78 - 21 = 57 years**

Average adult life span in U.S. - Age of eligibility for day services = Years receiving day services



**57 years X \$30,000 = \$1.71M**

Years receiving day services X Average annual cost of day services = An individual's lifetime cost for day services



**Residential funding beginning at 52 years old for 26 years**

Average life span (78) - Average birthing age in U.S. (26) = Age of ASD individual when parent dies

Age of ASD individual when parent dies (52) - Average life span (78) = Years receiving residential services



**26 years X \$60,000 = \$1.56M**

Years receiving residential services X Average annual cost of residential services = An individual's lifetime cost for residential services



**\$3.27M from age 21 to death**

Total cost of day and residential services combined from age 21 to death (age 78)

It's accurate that the high-functioning autistic child rarely receives residential funding unless he or she is in crisis. Crisis occurs definitively when parents of the ASD individual have passed away. Residential support dollars typically average approximately \$60,000 per year. If from the age of 52 for 26 years our high-functioning child is residentially supported, it will cost the state and federal government an additional \$1.56 million. In combination, the government will pay \$3.27 million for supports during the lifetime of the child with high-functioning autism.

Let's now look at this cost against 100 children. Let's first assume that a high-functioning qualifying student is sent to the state college life skills program at the cost of \$50,000 per year for six years or \$300,000 total.

## Redo!



### Enroll in a 6-year extended life skills college program beginning at age 21

ASD individual to enroll in an extended life skills college program similar to Scenic View Academy (Provo, Utah)



**6 years X \$50,000 = \$300,000**

Years enrolled in extended life skills college program X Average annual cost of program = Total cost for program per individual



### \$300,000 from age 21 to death if an individual successfully achieves independence

Total cost of services combined from age 21 to death (78) for an individual who successfully achieves independence

If we send 100 students for six years, the cost is \$300,000 per child or \$30 million for six years. If 50% of those children (50 students) become independent and the remaining 50% (50 students) do not, then the state and federal government will need to continue to fund the 50 students that need support for a total cost of \$184.5 million across these 100 students. Thus the total cost in a lifetime for 100 individuals would be \$184.5 million versus the traditional and current funding of \$327 million for the same 100 children. This results in a savings of \$142.5 million across 100 children. Never before has it been so apparent to me that the change for this crisis has to come from the top down, not from the bottom up.

While I feel confident in developing creative housing solutions to provide for success for our kids, without this massive educational restructuring, I do not personally or professionally see an end to this crisis. In closing, I also offer that we need both local zoning change and redefinition

of the Centers for Medicare and Medicaid Services (CMS) language with regards to our ability to develop creative housing solutions. The combination of effective change to these three areas will allow us to more successfully support our kids as well as others with special needs. ◀

## Let's just imagine...

We enroll 100 pre-qualified high-functioning ASD individuals into an extended life skills college housed within a college campus and we assume 50% of the population achieves total independence upon completion of the program.



### 50 ASD individuals who successfully achieve independence X \$300,000 = \$15M

50 ASD individuals who successfully achieve independence through completion of a 6-year program X Total cost for program = Total cost for 50 individuals to complete a 6-year program and no longer requires any supports



### 50 ASD individuals who do not achieve independence X \$3.39M = \$169.5M

50 program participants who did not achieve independence X (Total cost per individual to complete a 6-year program. Plus, 51 years of day supported services (ages 27-78) X Average annual cost of day services. Plus, 26 years of residential services (ages 52-78) X Average annual cost for residential services = Total cost for per individual for a 6-year extended life college program, day services, and residential supports from ages 21 - death (age 78).)



### \$184.5M for 100 individuals from age 21 to death

Total cost for 50 individuals who successfully achieve independence through completion of 6-year program + Total cost for 50 individuals who did not achieve independence = Total cost for 100 individuals from age 21 - death (age 78) where 50% are successfully independent

## Ta-da!

Without this strategy, 100 individuals currently cost our federal and state agencies \$327M for a life time of support. Isn't it worth a shot?!



### \$327M - \$184.5M = Savings of \$142.5M

Total cost of supports under current system for 100 ASD individuals - Total cost of supports for 100 individuals enrolled in a 6-year extended life skills college program assuming a 50% rate of achieving independence = Potential total cost savings