Barbara Crooker: Good morning.

IT'S 7:30AM ON A MONDAY IN FOGELSVILLE, PA. DAVID CROOKER, WHO IS 27 YEARS OLD, IS DOING HIS DAILY CHORES BEFORE HE HEADS OFF TO WORK. HE'S SO FOCUSED HE DOESN'T EVEN STOP TO SAY 'GOOD MORNING' TO HIS PARENTS...THAT'S BECAUSE DAVID HAS AUTISM. AND FOR HIM ROUTINE IS CRITICAL.

Barbara Crooker: What are you doing, Dave?

David Crooker: Putting out the trash

Barbara Crooker: Because it's...

David Crooker: Trash day.

CHORES COME EASIER FOR DAVID THAN CONVERSATION. AND THEY ARE MUCH EASIER THAN ANSWERING AN OPEN ENDED QUESTION ABOUT HIS FUTURE.

Producer: If you could do anything what would you do?

David Crooker: (WHISPERS) Oh, man. I take out the trash every Monday night.

Producer: You really like taking out the trash?

David Crooker: Yeah.

Producer: What do you like about taking out the trash?

David Crooker: Collecting all that baskets.

HIS MOTHER BARBARA CROOKER SAYS THAT ALTHOUGH DAVID IS AN ADULT, ON MANY LEVELS HE IS STILL A CHILD. SHE CAN'T ENVISION HIM EVER LIVING ON HIS OWN.

Barbara Crooker: He's extremely trusting. I-- I would be very concerned that for example it's pay day and someone says to him, "Well, Dave I don't have any money. Would you give me all your money?" And he would.

WHEN DAVID WAS DIAGNOSED AS A TODDLER BACK IN 1986, AUTISM WAS RARE: AFFECTING ABOUT 4 CHILDREN IN 10,000. AT THE TIME, DOCTORS GAVE BARBARA AND RICHARD A GRIM VISION OF THEIR SON'S FUTURE.

Barbara Crooker: They said essentially you could take him home and love him. And
then at some point you ought to let him go, you know, let him be institutionalized. And we drove home saying well, that's not going to happen.

SO BARBARA CROOKER LEFT HER JOB AS AN ADJUNCT COLLEGE PROFESSOR TO CARE FOR HER AUTISTIC SON, TRYING TO EASE HIS TANTRUMS AND HEAD BANGING, BEHAVIORS THAT ARE COMMON IN CHILDREN WITH AUTISM. ALTHOUGH THEY DIDN'T HAVE MUCH OF A ROAD MAP - THE FAMILY TRIED ANY TREATMENT THEY THOUGHT WOULD HELP - FROM ADAPTIVE GYMNASTICS TO ANIMAL ASSISTED THERAPY TO CHANGING HIS DIET.

Barbara Crooker: OK, you’re gonna get your vitamins in there, huh?

NOW THAT DAVID IS AN ADULT HER HUSBAND RICHARD - WHO'S RETIRED - HAS TAKEN OVER AS PRIMARY CAREGIVER WHILE BARBARA WORKS.

Barbara Crooker: So what it's amounted to though is that each of us lived half an adult life.

THE CROOKERS ARE AHEAD OF A WAVE OF HUNDREDS OF THOUSANDS OF FAMILIES WHO WILL SOON BE STRUGGLING TO CARE FOR ADULT CHILDREN WITH AUTISM. SINCE DAVID WAS DIAGNOSED IN 1980s, AUTISM RATES HAVE SOARED, TODAY ROUGHLY 1 IN EVERY 110 CHILDREN FALL SOMEWHERE ON THE AUTISM SPECTRUM, WHERE THE DISORDER CAN RANGE FROM MILD TO SEVERE. AS MANY AS HALF A MILLION OF THESE CHILDREN WILL REACH ADULTHOOD OVER THE NEXT 12 YEARS. AND THE COST OF CARING FOR THIS VULNERABLE POPULATION IS EXPECTED TO SURGE FROM AN ESTIMATED 1.3 BILLION THIS YEAR TO MORE THAN 26 BILLION BY THE YEAR 2023.

Peter Gerhardt, Ed.D. McCarton School: This is a very complex group of individuals that-- the system is in no way prepared to handle. You know, I-- I hate to use the analogy of-- of a tsunami, but that's really what it-- what it is. And it's not like we can't see it coming.

PETER GERHARDT IS THE EDUCATION DIRECTOR OF A SCHOOL FOR AUTISTIC CHILDREN IN NEW YORK CITY. A PIONEER IN THE FIELD, HE HAS BEEN WORKING WITH AUTISTIC TEENAGERS AND ADULTS FOR MORE THAN 30 YEARS.

Peter Gerhardt, Ed.D.: You go through the educational years, and you have all these supports, and you have all these very well qualified professionals to work with you. You enter the adult world, and there's no guarantee of services. Funding gets cut dramatically. It is like falling off the cliff.

THE FACT IS FEDERAL LAW REQUIRES STATES TO PROVIDE SERVICES FOR CHILDREN WITH AUTISM THROUGH THE EDUCATIONAL SYSTEM – BUT ONLY UNTIL THEY REACH THE AGE OF 22.
Alison Stewart: People who are at home might be wondering why don't people with autism fall under the systems provided to people with other disabilities?

Peter Gerhardt, Ed.D.: They do. But the problem is their needs are more intense than people with other disability labels, usually. And also, the system that's designed to support adults doesn't have the funds to support people. They're it's not an entitlement system. There's no guarantee, so it really is a system where we will provide services if we have the money to do it. And in our current economic climate, that's a big if.

SERVICES TO HELP ADULTS WITH DEVELOPMENTAL DISABILITIES LIKE AUTISM VARY WIDELY FROM STATE TO STATE. OVER THE LAST THREE YEARS, AT LEAST 10 STATES HAVE CUT FUNDING FOR PEOPLE WITH DISABILITIES.

Peter Gerhardt, Ed.D.: When we hit our fiscal crisis one of the first things that states looked to cut was were Medicaid services. Medicaid services are what funds adult services for people with development disabilities. So, we have a system that's already overwhelmed that's going to get more overwhelmed and has fewer resources.

Alison Stewart: Let's talk about the current state of the system. Is it adequate currently?

Peter Gerhardt, Ed.D.: No. No, the system right now is not adequate. Kids are still graduating out and staying at home. Right now, we have a system that, best case scenario, gives you, sort of, the minimal services.

Alison Stewart: Worst case scenario?

Peter Gerhardt, Ed.D.: You get no services.

FOR DAVID CROOKER, BEING IN THE EDUCATIONAL SYSTEM MEANT A TEACHING ASSISTANT TO COACH HIM EACH DAY, SPEECH AND OCCUPATIONAL THERAPY, AND GUARANTEED TRANSPORTATION. GRADUATION ENDED ALL THAT. IT ALSO MEANT THE END OF THE WORK STUDY JOBS HE HAD ALL THROUGH HIGH SCHOOL.

Barbara Crooker: He was placed in a variety of different work study experiences none of which were with organizations that were willing to offer jobs. They wouldn't even take an application after school was done.

EVENTUALLY, PENNSYLVANIA'S OFFICE OF DEVELOPMENTAL PROGRAMS PLACED DAVID HERE AT GOOD SHEPHERD WORKS SERVICES. IT'S A NON-PROFIT ORGANIZATION THAT PROVIDES WHAT'S KNOWN AS SHELTERED WORK WITH SUPERVISION AND COACHING SPECIFICALLY FOR PEOPLE WITH DISABILITIES.

Barbara Crooker: We're very happy with the people at Good Shepherd Work Services. They're very kind to him. But that wasn't our goal. Our goal was community
employment, a real job.

FOR ADULTS WITH AUTISM, A JOB IN THE COMMUNITY IS TOUGH TO COME BY. AUTISM ADVOCATES ESTIMATE THAT THE UNEMPLOYMENT RATE FOR PEOPLE ON THE AUTISM SPECTRUM IS AS HIGH AS 80-90 PERCENT.

Peter Gerhardt, Ed.D.: We need to do a much better job interacting with the business community -- to get the message across that we have this pool of, potentially, really competent people who could benefit your business. People with autism are probably some of your best employees.

David Crooker: I made more than ten trays of boxes of eight markers.

Producer: And do they go by certain color or?

David Crooker: Certain color, yeah.

WHILE DAVID IS SETTLED AT WORK FOR NOW, THE LOOMING QUESTION IN HIS FUTURE IS WHAT WILL HAPPEN TO HIM WHEN HIS 65-YEAR-OLD MOTHER AND 68-YEAR-OLD FATHER ARE NO LONGER AROUND TO CARE FOR HIM.

Barbara Crooker: I've actually been told by social workers, not my current one, but previous ones that the plan really is don't die. But that doesn't seem to be a very realistic plan does it?

TODAY DAVID IS ON PENNSYLVANIA’S WAITING LIST TO GET A SPOT IN A GOVERNMENT-FUNDED RESIDENCE. HE’S BEHIND MORE THAN 4000 PEOPLE, WHOSE NEEDS ARE CONSIDERED MORE URGENT BY THE STATE.

Barbara Crooker: Everybody’s on a waiting list. The waiting list is so long that you realize that you wouldn’t reach it in your natural lifespan.

NATIONWIDE, THERE ARE MORE THAN 120 THOUSAND PEOPLE WITH DISABILITIES ON WAITING LISTS FOR RESIDENTIAL SERVICES.

Alison Stewart: Right now, it’s true that most people with autism under 30 still live with their parents correct?


Alison Stewart: And will likely continue to have to live in their parents' home or a family member's home given the current system.


BARBARA SAYS SHE INVESTIGATED THE POSSIBILITY OF PAYING FOR A RESIDENTIAL PLACEMENT FOR DAVID OUT OF HER OWN POCKET. BUT THE PRICE WAS OUT OF REACH.
Barbara Crooker: It’s about $35,000–$40,000 a year, times 60 years, average lifespan—and we’re looking at easily $2 million. And I don’t see that in the general population that there are people with extra $2 million, who aren’t rock stars, sports stars, CEOs and things like that.

THE CURRENT PLAN FOR DAVID WHEN HIS PARENTS ARE GONE IS TO LIVE IN NORTH CAROLINA WITH HIS SISTER BECKY, WHO HAS A FULL TIME JOB. HIS OTHER SISTER STACEY, WHO LIVES IN NEW JERSEY WITH TWO CHILDREN OF HER OWN, WILL MANAGE HIS FINANCES.

Barbara Crooker: His sisters will become his guardians. We will leave our estate in trust for him. And we-- we do know that they will do the best they can by him because these are two great young women. And-- and they’re very fond of their brother. But I also know it’s going to be probably presenting a hardship for them.

AND FOR DAVID THERE’S ANOTHER HARDSHIP. A MOVE TO ANOTHER STATE LIKE NORTH CAROLINA TO BE WITH HIS SISTER MEANS DROPPING TO THE BOTTOM OF THE WAITING LIST FOR SERVICES THERE. BARBARA, WHO’S A PUBLISHED POET, WROTE ABOUT THE WEIGHT OF HER WORRY OVER DAVID’S FUTURE IN A POEM CALLED "PUSHING THE STONE."

Barbara Crooker reading poem
The stone
was heavy.
The family carried it
with them all day.
Not one
could bear
it’s weight, alone.
Yet how they loved it.
When the mother’s back ached,
the father took the stone
for a while, then passed it
from sister to sister.

Barbara Crooker: I was thinking of the myth of Sisyphus, where Sisyphus has to push the stone up the mountain every day, and then at night it rolls back down and in the morning you have to go roll it up again. For me the stone is his future, the weight of his future. Because it’s one that I-- am incapable of doing anything about.

THROUGHOUT THE COUNTRY, PARENTS OF AUTISTIC ADULTS ARE STRUGGLING WITH THIS SAME WEIGHT.

Mary Wallan: OK, you cut it up in some nice big pieces

59-YEAR-OLD MARY WALL AN AND HER 68-YEAR-OLD HUSBAND PETER LIVE OUTSIDE BOSTON WITH THEIR SON JOE WHO HAS AUTISM.
Mary Wallan: Fingers back—bigger than that.

BUT UNLIKE THE CROOKERS, THEY HAVE NO OTHER CHILDREN TOTAKE CARE OF JOE, WHO IS NOW 23, WHEN THEY ARE GONE.

Mary Wallan: Nope, that’s good.

Peter Wallan: It’s not an onion.

Joe Wallan: It is an onion.

Peter Wallan: No, what color is an onion?

FIGURING OUT WHERE AND HOW JOE WILL LIVE IN A WORLD WITHOUT THEM IS THEIR TOP PRIORITY.

Joe Wallan: Can you let me do my job?

Mary Wallan: We are.

THEY WANT TO HAVE IT SETTLED WHILE THEY ARE STILL HERE TO HELP HIM THROUGH THE DIFFICULT TRANSITION.

BUT ALTHOUGH JOE IS TECNICALLY ELIGIBLE FOR GOVERNMENT-FUNDED HOUSING, HE’S LOW ON THE PRIORITY LIST. SO LOW, HIS PARENTS SAY THE ONLY WAY HE’D GET IT WOULD BE IN AN EMERGENCY – FOR EXAMPLE IF THEY BOTH DIED SUDDENLY. AND THAT POSSIBILITY IS WHAT SCARES THEM MOST.

Mary Wallan: We worry that he might be-- have to be housed by the state in an emergency situation, which just completely goes against the grain for a person with autism. You need to prepare them. You need to plan. You need to let them know what it’s going to be like.

FACED WITH A LACK OF OPTIONS, THE WALLANS - LIKE MANY PARENTS OF ADULTS WITH AUTISM – ARE HOPING TO CREATE THEIR OWN SOLUTION. THEY PLAN TO JOIN WITH OTHER PARENTS AND TOGETHER FUND A GROUP HOME FOR JOE AND OTHER AUTISTIC ADULTS. THAT MEANS NOT ONLY COMING UP WITH THE MONEY – BUT MAKING SURE JOE CAN SAFELY BE ON HIS OWN FOR BRIEF PERIODS OF TIME.

Mary Wallan: Is it too hot?

Joe Wallan: Yeah.

Mary Wallan: In looking into housing for adults, it’s-- it’s become really clear that he
needs to be much more independent than he currently is.

**Teacher:** Get to it.

**TO HELP PREPARE JOE FOR LIFE WITHOUT THEM, THE WALLANS HIRED JOE’S FORMER TEACHER TO WORK WITH HIM ON THE SKILLS OF DAILY LIVING.**

**Joe Wallan:** Check to see if washer is empty.

**EVERY TASK IS BROKEN DOWN INTO STEPS.**

**Joe Wallan:** It—so it’s not empty.

**Teacher:** It’s not empty or it is empty?

**Joe Wallan:** It is empty.

**Teacher:** Okay.

**A LIST ON THE WALL PROVIDES A VISUAL CUE TO HELP HIM.**

(Joe sorting clothes)

**Joe Wallan:** We’re going to sort the clothes: white, colored…It’s white

**Teacher:** Good job.

**Joe Wallan:** It’s dark. *(Places in the light basket)*

**Teacher:** Uh-uh.

**Joe Wallan:** It’s dark. *(Places in the light basket)*

**Teacher:** There you go.

**Joe Wallan:** It’s green.

**Teacher:** Good job.

**Joe Wallan:** Thank you for giving me a compliment.

**Teacher:** Thank you for doing your work.

**Teacher:** For Joe and for other adults with autism, they have to be taught very systematically.

*(Reading list)*
Joe Wallan: Put the clothes in washer.

Teacher: Okay, so which one has more clothes—that one or this one?

Joe Wallan: This one?

Teacher: You got it.

Teacher: Joe and I also work on reading facial cues in others and social interactions.

Teacher: So if anybody asks you for money what are you going to say?

Joe Wallan: Like, I’m sorry, I can’t give you money—right?

Teacher: Who can you give money?

Joe Wallan: Maybe my mom or dad but I can’t give money to Amanda.

Teacher: Or anybody else, only mom and dad, if mom and dad ask for money.

Joe Wallan: Okay.

JOE IS ALSO HONING HIS INDEPENDENCE SKILLS AT A JOB HE HAS AT SHAW’S SUPERMARKET IN SOMERVILLE, MASS.

Joe Wallan: I need help with that, Justin, if you could help me a little?

AUTISM SERVICES ASSOCIATION, A LOCAL NON-PROFIT, ARRANGED THE JOB PLACEMENT AND PROVIDES HIM A PERMANENT JOB COACH.

Justin Pespisa: Joe, wait here.

Joe Wallan: Sometimes I have a difficult time with crossing streets, and one thing we’re workin’ on, you know, not asking a guy for help.

Justin Pespisa: Alright Joe what are we going to do before we cross?

Joe Wallan: You have to look right?

Justin Pespisa: Have to.

ON THIS MORNING JOE IS GRAPPLING WITH ANOTHER ISSUE COMMON FOR ADULTS WITH AUTISM. JUSTIN PESPISA HAS BEEN COACHING JOE FOR 5 MONTHS – BUT IS NOW LEAVING TO GO TO MEDICAL SCHOOL.

Joe Wallan: When’s your last week Justin?
Justin Pespisa: This one.

Joe Wallan: So, are you going to be here tomorrow?

Justin Pespisa: Yup, I’ll be here tomorrow Joe.

Joe Wallan: Well when’s your last week, I was wondering.

Justin Pespisa: This week is my last week.

Joe Wallan: Not my last week right?

Justin Pespisa: No, you’ll be here.

THE ANNUAL TURNOVER RATE FOR STAFF WORKING WITH AUTISTIC ADULTS IS ABOUT 50 PERCENT – AND THAT MEANS CONSTANT CHANGE FOR PEOPLE LIKE JOE – WHO DEPEND UPON THINGS REMAINING THE SAME.

Justin Pespisa: Alright you lead the way, Joe. I don’t want you following me around. You know what to do.

WHILE HIS PARENTS ARE HOPING THEY WILL BE ABLE TO EASE JOE INTO A LIFE INDEPENDENT FROM THEM – THEY KNOW JOE’S FUTURE IS FAR FROM SECURE.

Mary Wallan: Whether he can actually make that cut and survive in a less-supervised house remains to be seen. But we’re being optimistic and trying to bring him along, hoping that he can do it.

Peter Wallan: My two worries for him are-- are that he be safe and that he be happy. That’s-- that’s the bottom line for me.

TO MAKE THAT HAPPEN, THE WALLANS KNOW THEY’LL HAVE TO CONTINUE FIGHTING FOR THEIR SON’S FUTURE. BUT GIVEN THE CURRENT ECONOMIC AND POLITICAL CLIMATE, THEY WORRY THAT WHATEVER THEY DO WON’T BE ENOUGH.

Mary Wallan: Every year, we’re expected to go to rallies, contact our legislatures, bring our kids out. And it’s like there’s no memory, you know, of the previous year. It’s like our-- our kids are still there. We still need to help. But we need to fight, fight, fight, fight, fight to make sure there’s some level of funding for them there.

THE QUESTION IS: WHAT WILL HAPPEN WHEN PARENTS LIKE THE WALLANS AND THE CROOKERS ARE NO LONGER AROUND TO FIGHT?

Barbara Crooker: We’re going to see in -- in-- maybe 20 years the half a million or so parents like us are going to be gone, and all of these children who are going to be
middle aged adults at that point are gonna need some sort of services. And we're a big elephant in the room, because nobody is planning for this.