

The government is working to better understand how people interact with its services to improve the customer experience (CX).

People with disabilities and their families receive critical support from the government, interacting with agencies at the Federal, state, and local level. At times, this can be challenging for individuals and their families to understand the full scope of what support is available and to decide what is right for them. Individuals and their families must research, apply, and weave together support from each agency individually over the course of their life.

This journey shows a person with an intellectual disability, who has limits in their ability to learn and function in daily life, transitioning from childhood to adulthood. This transition period has been described as a “cliff,” with the policies, protections, and supports provided during school ending. This phase is full of big decisions that influence the rest of the person’s life, making it particularly challenging to navigate.

WHO IS IMPACTED BY THIS JOURNEY?



7–8 million people

in the U.S. have an intellectual disability



50+ delivery systems

The delivery system for those with disabilities varies drastically across states and even counties. Said one interviewee: “You literally cross one county line to another and the availability of services is so different... not everyone can move.”



45+ programs

The Federal government has 45+ programs to support people with disabilities



\$70B spent annually

Taxpayers spend \$70B annually on resources for people with intellectual and developmental disabilities, with over half being provided at the Federal level

WHO IS INVOLVED IN THIS JOURNEY?

Local*

- County Boards of Developmental Disability
- School Districts
- Community Providers

State*

- Developmental Disability Agency
- Department of Education
- Department of Health
- Medicaid Office
- Vocational Rehabilitation (VR)
- Workforce Agency

Federal

- Centers for Medicare & Medicaid Services (CMS)
- Department of Education (ED)
- Department of Health and Human Services (HHS)
- Department of Labor (DOL)
- Social Security Administration (SSA)

* The titles of the organizations vary by locality and state

WHO DID WE SPEAK TO?

- PEOPLE WITH DISABILITIES
- PARENTS
- AGENCY LEADERS
- SERVICE PROVIDERS
- ADVOCACY ORGANIZATIONS
- SUPPORT COORDINATORS
- TRANSITION COORDINATORS



24

Interviews



334

Survey responses



5

Iterative design sessions with over 20 Federal employees



ABOUT JOURNEY MAPS

What is a journey map and how do you read it?

Journey maps serve as a summary of the voices of actual customers and represent their experiences at points along a series of steps across some time period. When reading this journey map, the actions show the high-level steps along the journey, while the other elements reveal research insights that can inform opportunities for improvement.

Learn more: [Performance.gov/2020cxmaps](https://performance.gov/2020cxmaps)
Contact: CX@omb.eop.gov

What is a journey map and how do you read it?

The Federal Customer Experience Initiative team, led by the Office of Management and Budget, partnered with more than 10 agencies for a human-centered approach to improving critical moments in our customers’ lives. The research and production of this visual journey helps align our understanding of how a public service delivery system is experienced by the public. Through identifying common barriers, we can improve coordinating efforts across the Federal government.

How will this journey map be used?

Although it’s difficult to re-design complex delivery systems, specific barriers along a journey can indicate areas that matter most to the people we serve. The journey shows that more broad interagency efforts (e.g., on “Veterans employment”) can be slower to deliver changes than scoped challenge areas (e.g., “better connecting job searching platforms”). We plan to form interagency design teams that convene experts to prototype and test solutions for streamlining services.

CUSTOMER JOURNEY: PERSON WITH AN INTELLECTUAL DISABILITY

Claire, Dan, and Kimberly are blended characters that represent common themes found across multiple interviews.

Claire



Age 16 | Junior in High School

West Virginia

Claire has an intellectual disability that was identified when she was four. She loves being involved in extracurricular activities at school, so this year with COVID-19 has been particularly challenging. Claire's mom took off work for six weeks at the beginning of the lockdown to help her establish a new normal.

Claire's mom applied for a Medicaid waiver when she was five, however it took Claire eight years to get off the waitlist and it "was silence until the end." Since she began receiving Medicaid waiver services, "it's been a HUGE help."

Claire receives Supplemental Security Income (SSI) and is learning how to drive with the help of waiver services. Over the summer, she works part-time at a local restaurant bussing tables. She'd like to take on more hours, but she's "frustrated she can't work more without losing SSI." Her mother asked her to "stop working altogether to make sure she is able to receive SSI for life." As the family is getting older, she "wants to make sure she'll be ok if something happens to her."

Claire was on the waitlist for eight years before receiving Medicaid waiver services and must limit the number of hours she works in fear of disqualifying herself from SSI.

Dan



Age 50 | Father | Engineer

Texas

Dan is a father of three. One of his sons, Josh, is a freshman in high school and has cerebral palsy. When Josh was diagnosed, Dan started attending a family support group. He's found the group to be his "safe space where he's found the most valuable information and advice." Josh receives SSI and Medicaid waiver services and Dan really struggles to keep up with all of the paperwork as his representative payee. He "has to take off work because some tasks can't be accomplished during the weekends." One of Dan's pet peeves is that "all of the forms and documentation pull him away from giving Josh the care he needs."

Josh needs a caregiver to help him with physical and developmental needs. Dan's "biggest frustration has been caregiver turnover." When he does find someone and they're a great fit, they quickly move on to find something that pays more or to get a degree, and they have to meet someone new. Last year, Dan and his wife decided that he would work the night shift at his job so he could care for Josh when he got off the school bus until his mom got home from work. "It's not ideal, but we're making it work."

Dan finds solace in his family support group, struggles to manage the paperwork for his son to continue to receive government support, and struggles with caregiver turnover.

Kimberly



Age 43 | Mother | Teacher

Indiana

Kimberly is a single mother with three children. Sam, her eldest, is a senior in high school and has down syndrome. Kimberly has been exploring supported-decision making options for Sam in lieu of obtaining guardianship. She is active in the special needs community to connect with "people in the same boat as [her]". She expressed, "I just want her to be treated with respect and have this fear that if I have guardianship, they're not going to take her feelings into consideration. I don't want her to lose having respect and being treated like any other human. She's a human being, I want her opinion to count."

Kimberly has also been planning for what Sam will do during the day after high school. The last two years, Kimberly went on two "field trips" organized by her school transition coordinator to "get a feel for what's out there after high school." The first trip was more about "seeing what options existed" while the second was to "hone in on options that are a great fit for her." They decided that Sam will live at home next year and attend a learning center during the day. The program facilitates learning experiences in the community and practicing life skills like cooking and gardening. Sam already has a few friends in the program.

Kimberly examines supported-decision making options in lieu of guardianship and explores options for what Sam can do after she completes high school.

CUSTOMER JOURNEY: PERSON WITH AN INTELLECTUAL DISABILITY

EARLY CHILDHOOD

TRANSITION FROM CHILDHOOD TO ADULTHOOD

AGING

STAGE

Prepares for Transition
Ages 14 - 17

Transitions to Young Adulthood
Ages 18 - 22

Cultivates Independence
Ages 23+

⚖️ Weighing Your Options

Individuals and families struggle to find clear guidance on transition options; to navigate decisions after high school, they lean on their network(s) and those who have gone through the process before.

“When I look for resources online, it’s so overwhelming and information is everywhere. I usually just ask people I know that have gone through it.”

– Dana

✓ Making Tough Choices

Individuals and families grapple with difficult decisions related to becoming a legal adult and struggle to find people within government with whom they can work to determine the best option(s).

“I’m really struggling with taking all of his rights away. Once you get guardianship, you strip them of their rights, and it’s very hard to get them back. That makes me feel uncomfortable.”

– Annette

♥️ Patching Together and Sustaining Care

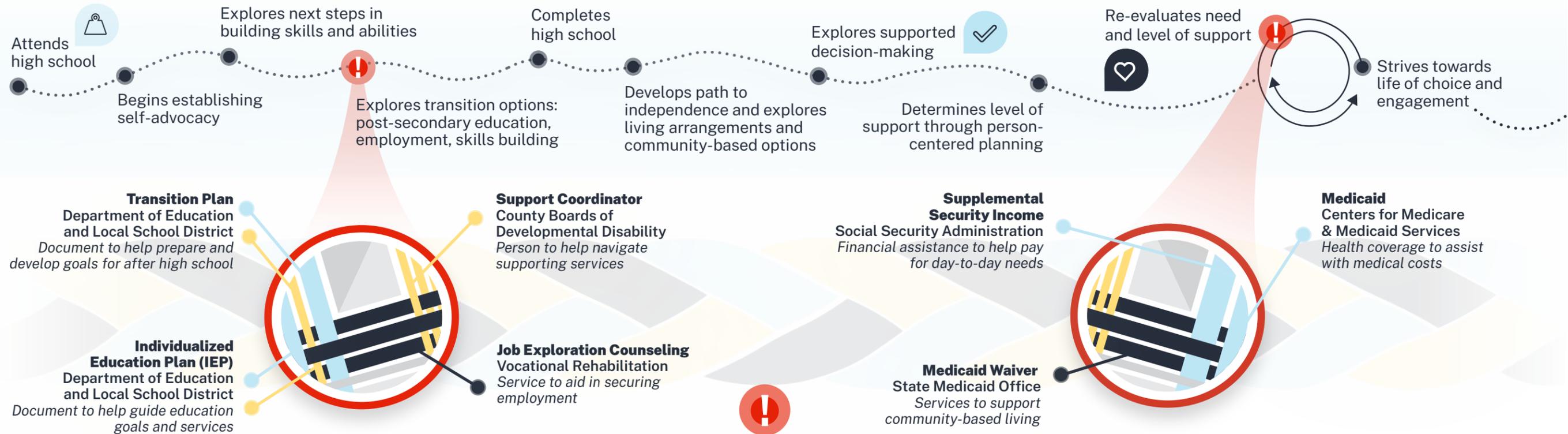
People with disabilities and their families dedicate large amounts of time and resources to continue accessing government support.

“You have to fill out an identical 20 page application 8,000 times for everything you ever apply for. I had to start working part-time to manage it all.”

– Anonymous (mother)

MOMENT THAT MATTERS

ACTION



GOVERNMENT & EXTERNAL SUPPORT

In these moments, **the burden is on individuals and their families** to braid together services and support

CROSS-AGENCY CHALLENGES

FRAGMENTED SERVICES & INFORMATION

Government services and information are siloed, making it difficult for people to have a complete picture of what support is available. “Information is all over the place and government websites are text-heavy, nebulous, and TLTR (too long to read). We need a checklist with things we should do every year.”

– Andrew

FIXING ISSUES THAT COULD HAVE BEEN PREVENTED

People are connecting with government support too late, resulting in spending more time and resources fixing issues that could have been prevented. “I spend so much time working with families to fix things that could have been prevented if they just started working with us sooner.”

– Nicole

NOT DESIGNED WITH STRESS IN MIND

People are stressed and not in the frame of mind to process complex information, making it difficult to navigate government processes. “It’s constantly in the back of my mind and something I prepare for—who is going to take care of her when I’m gone?”

– Anonymous (mother)

DISJOINTED ELIGIBILITY

People are proving their eligibility to multiple agencies, creating an undue burden on families to submit repetitive documentation and unequal eligibility across states. “We can choose to shop states [to receive the best services], but that’s not an option for a lot of people.”

– Susan

OVER-EMPHASIS ON FRAUD PREVENTION

Government processes are designed to prevent the small percentage of fraud, resulting in an undue burden for the large majority of good actors. “I wish there was a Global Entry for this. Look at my record—I’ve proven I’m trustworthy. Can you please cut me some slack with all of this paperwork?”

– Andrew

UNNECESSARILY LOSING RIGHTS

Families are often being steered towards guardianship, resulting in many people unnecessarily losing their rights. “The State services agency started on me when she was 18—said I needed to obtain guardianship. So I did it... they’re the experts! And now I totally regret it.”

– Anonymous (mother)