

2020 Partners in Disability Leadership Yearbook

A MESSAGE FROM PDL PROGRAM LEADER GINGER MAYEAUX

I am honored to have had the opportunity to get to know so many amazing leaders in disability field. Over the past six months, I have learned as much from each and every one of you as I have from the many nationally recognized speakers. Seeing your creativity, values, and passions come to fruition in your leadership projects gives me hope for the future of Texans with disabilities. Congratulations on your hard work and dedication. I look forward to seeing the many wonderful things you will do, and am proud to call you partners!



Ginger Mayeaux, Director of Public Policy & Advocacy for The Arc of Texas



PARTNERS IN DISABILITY LEADERSHIP

A Program of **The Arc.**
Texas

Congratulations, PDL graduates!

“Thank you for your commitment to improving the way Texans with intellectual and developmental disabilities and their families receive the services they need.” -*The Arc of Texas CEO Jennifer Martinez*



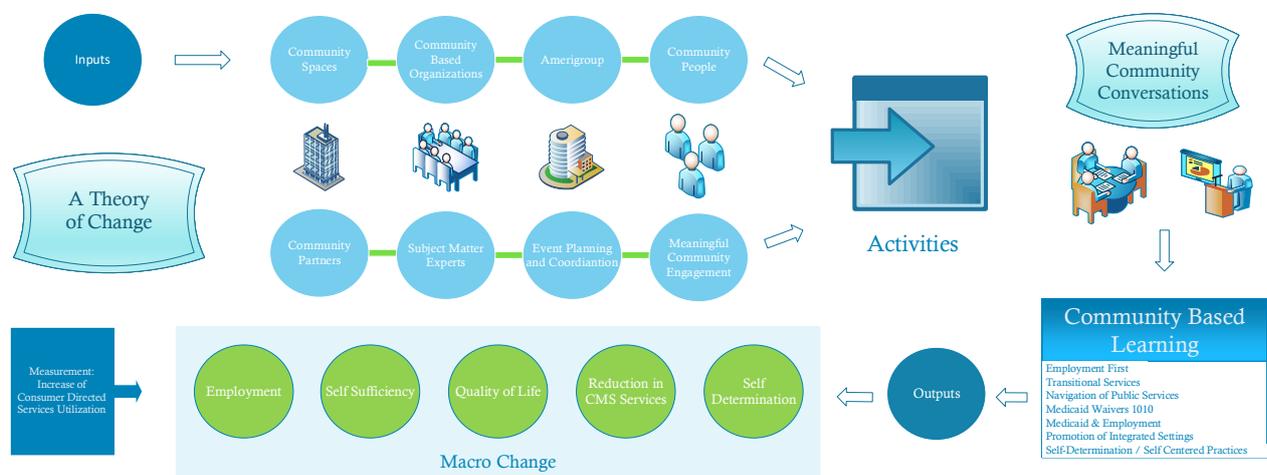
Jennifer Martinez, CEO of The Arc of Texas

It is my great pleasure to congratulate you on your graduation from The Arc of Texas’s inaugural Partners in Disability Leadership program! This marks an important career milestone you have achieved during an unprecedented year of challenges. From the start, each of you have shown not only unwavering dedication to learning and growing, but also an incredible resilience that inspires us all. We are honored that you chose to pursue leadership training with The Arc of Texas. We cannot wait to see the incredible strides you and your peers will make in the weeks, months, and years ahead.

Thank you for your commitment to improving the way Texans with intellectual and developmental disabilities and their families receive the services they need.

the self-determination series EMPOWERING COMMUNITY MEMBERS TO ACCESS AND NAVIGATE HEALTH SERVICES AND RESOURCES

by Roger DeLeon



With the assistance of my employer Amerigroup, we will be creating focus-group outreach events.

It is vital to have meaningful stakeholder engagement in the community and discuss what is important to them. The “Self Determination Series” will be open to all people. The events will enable the community to navigate Texas health and social services; at the same time teaching the community to self-advocate, have freedom of choice, and a step towards independence. The events will be held periodically in Amerigroup operating market areas in Texas with the assistance of our community-based organizations as our subject matter experts. The focus groups will have an emphasis on:

- **Employment First** Seek employment, work in competitive or integrated settings.

- **Promotion of Integrated Settings** Engage in community life and receive services in the community (day habilitation services).
- **Consumer Directed Services (CDS)** option and control their personal resources; person-centered, self-determination, self-directed.
- **Transition Services** Facility to Community/School to Community.
- **Navigation** of public services.
- **Developmental Disability Medicaid Waivers 101.**
- **Employed and on Medicaid** Work Incentives Planning & Assistance (WIPA) and Protection and Advocacy for Beneficiaries of Social Security (PABSS).

SELF-DETERMINATION AND SELF-ADVOCACY

by Tina Carter & Mendy Blank

This project was created as a result of the identification that sometimes individuals with IDD are not aware of their rights, have limited involvement in their service planning, and do not know how to advocate for their wants and needs.

Ultimately, the project goal is for all individuals with IDD, with the support of their family members, guardians, service coordinators, and service providers, to know their rights and be able to advocate for themselves; to connect with peers and hear how self-advocacy has positively impacted others; to give and get advice; and to feel supported and heard.

Keynote speakers who are individuals with personal and professional experience in the field of IDD and self-advocacy are essential to the success of the project.

Ricky Broussard, known throughout Texas for his work and legislative advo-

cacy will present on Freedom and Authority with a focus on the principles of self-determination to an audience of individuals receiving waiver services.

Presentations intended for families and providers will be offered by Lauren Gerken. Lauren, a Public Policy Analyst for the Texas Council for Developmental Disabilities, will share her knowledge speaking about empowering people with disabilities and eliminating barriers through her presentations titled *Changing the Narrative* and *Shattering the Myths*.

We hope to continue to support persons with disabilities to exercise control over their own lives. We plan to achieve this by providing continual follow up with people interested in learning how to become self-advocates, as well as enabling them to build a support network with other self-advocates.

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INCLUSIONARY PRACTICES THROUGH A NEW LENS

by Karlyn Keller, Ed.D.

My project focused on a deep dive on inclusionary practices within my organization with a new lens. At the Texas Association of School Boards, we work with just about every school district in our state, nearly 1,200 of them. Supports and services range from School Board and staff training, policy writing, and legal support to risk management, facilities and school Medicaid. With almost 500 staff members here in Austin and across this great state, we are the largest educational association in the state and the largest School Board association in the United States. This project was an inside out review of our association to identify potential gaps and how we can address those gaps as it relates to supporting an inclusionary practice for individuals with disabilities.

KNOWING YOUR COMMUNITY LIVING OPTIONS

by Amanda Morphew

My project is about connecting with individuals with IDD who reside in nursing facilities to help aid them in learning about the different community living options that are available to them.

The current process is that residents get handouts presented to them that show different pictures of where they can live, but there is nothing specifically for our area. I will be coming up with virtual tours of the different residential options in our area, as well as interviewing those that live by themselves or with a foster care provider to talk about their experience with community living.

My hopes for this project are to connect individuals to the least restrictive environment possible, so that they can achieve their highest quality of life and get to live in the community and be connected to services that can help benefit them.

INCLUSIVE PUBLIC HEALTH PROGRAMMING INITIATIVE

by Cassandra Johnson

People with disabilities are more likely to have health conditions or risk factors that public health programming targets, such as smoking, hypertension, obesity, fall-related injury, depression, and diabetes. The State of Texas has programming for issues such as these, but the programs typically do not have a strategy for targeting people with disabilities. This project is the beginning of a workforce development initiative which transforms the culture of the public health workforce in Texas toward considering people with disabilities when creating and implementing public health programming – particularly in those areas where people with disabilities are at higher risk

DENTON COUNTY MHMR 2021 RESOURCE PACKET

by Hannah Roundtree

Currently, and for the last several years, the Denton County MHMR resource packet has focused primarily on providing resources for mental health supports and services only. Currently, within Denton County MHMR's sixty-four page resource document only four pages are dedicated to IDD supports, services, and resources. Of the limited resources listed for IDD many are outdated or contain language that is considered offensive and politically incorrect regarding the IDD community. The purpose and goal of my leadership project is to 1) locate and research new, additional resources for individuals and families 2) create an atmosphere of inclusivity throughout the entirety of the packet 3) update language regarding IDD throughout the packet. This will be the first time within the last several years that a staff member from IDD services will participate in updating the center's resource packet. This project has typically been completed by mental health staff only, resulting in misinformation and loss of opportunity to create a more connected and inclusive center.

ACCURATE REPORTING OF INDIVIDUALS INCARCERATED WITH AN IDD DIAGNOSIS

by Christopher Anderson

Currently, there is a deficit in data that accurately reflects the number of individuals who are either arrested or incarcerated with a primary diagnosis of an intellectual or developmental disability. This misrepresentation directs attention away from the significant need for effective community services and supports that this population needs to avoid arrest and incarceration.

If there was a continued effort to accurately identify individuals with a diagnosis of an intellectual or developmental disability and not just a mental illness, this could potentially lead to a better representation in data of a

population needing more supports than what is currently accessible. This would also potentially provide a substantial argument that additional funding for the IDD population could lead to more effective person-centered services and supports, both immediate and long term, directing statewide funding to areas of service most beneficial to the IDD population.

In addition, this would help identify where training is needed in the Texas Judicial System for those who come in contact with this population upon being arrested.

Additional concerns with the inaccurate representation of the IDD population is

the lack of an effective plan to quickly divert individuals who have been arrested from an environment that can potentially put these certain individuals at risk of traumatization.

My proposal is to create a system at the local level in collaboration with the LMHA/LIDDA, Texas Department of Criminal Justice, and local CRCGs that can be duplicated across the state in hopes of filling a gap in services and supports needed for the IDD population while also collecting data to support the need for additional funding of IDD support and services in the state of Texas.

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BRIDGING THE GAP

Home and Community Services & Texas
Home Living Regional Collaboratives Project

PROJECT PARTICIPANTS

Jennifer Marshall
**Jennifer Chancellor-
Hurd**
Erin Perez
Joy Kearney
Kendrah Buckley
Jennie Costilow
Elaine Wied
Phyllis Matthews
Jessica Morse

The Partners in Disability Leadership participants from the Health and Human Services Commission worked together on the Regional Collaboratives Project. This project will close the gaps in service and care coordination by providing training, educational materials, and contacts necessary for service and care coordination entities to successfully work together to ensure optimized, purposeful and meaningful supports and services which support individuals with intellectual and developmental disabilities (IDD) who participate in the Home & Community-based Services and Texas Home Living waiver programs to have their personally chosen, desired life. This project is anticipated to culminate in one or more Regional Collaboratives in which Local IDD Authorities, Medicaid managed care organizations, private providers, advocacy organizations, and individuals receiving services will participate in a virtual forum structured to strengthen relationships and increase knowledge of programs, services, resources, and responsibilities.

JMCH JUVENILE BENCH BOOK

by Angelita Hunter

There are an overwhelming number of juveniles being charged at school. When law enforcement involvement is requested, these officers are not equipped with any assessment tools to allege one's culpability and are often not aware of the functions of, or protections under, an Individualized Educational Plan with a Behavioral Intervention Plan, or an Individualized Health Service Plan. It is not typical for police departments to employ or inquire with medical professionals after a juvenile is made known to have an IDD. There is no accountability for an officer's signature to allege that culpability exists. If charges are filed, the DA or prosecutor are often unaware of IDEA and the special educational laws governing and providing federal protections, and judges overseeing these cases may likewise be unaware of the full extent of special education law or IDEA to assist the juvenile with IDD. With these incidents occurring at staggering rates, we are unknowingly watching each intercept of prevention being lost in the translation. The personhood is damaged, and community inclusion becomes harder with the known or unknown bias that is now accredited to the juvenile.

My project outlines the components that will assist in connecting these different spheres in a community, acknowledges the ineffective practices and discounting, provides guidance on unknown services

“In truth, IDEA is effectively the only parentally enforced federal law on the books.”

John McLaughlin

and resources, and ultimately tries to de-tour juveniles from entering or re-entering the criminal justice system by assisting in the creation of the Judge's Juvenile Bench Book. With the sequential intercept model, all stakeholders can collaborate, share resources and ideas, and create a partnership between agencies. With a community practice model, all community members can assist in the inclusion and personhood of these children.

You cannot force a community to do anything. You can only create a culture of your beliefs and provide the language for it. All community members should be active participants to hear this part of the conversation. This is how I, a parent of a child with IDD who has lived this experience and been a consumer of this product, measures my success, but also how we measure our success as professionals.

Meet the PDL Grads

Why join The Arc of Texas Partners in Disability Leadership program? Members of the 2020 class explain their background, motivations, and goals for participating in this inaugural group.



“I supervise a team of four service coordinators for the local intellectual and developmental disability authority (LIDDA). Person-centered planning and advocacy is at the heart of what we do at PermianCare. I want to lead my team to ensure the people we serve are supported in making decisions for themselves and that are important to them and their families.”

Amanda Morpew
Service Coordinator Team Leader



“I am interested in assisting and identifying gaps in the criminal charges stemming from schools and children with disabilities. I am hoping to provide data-based influence that will assist with systematic change.”

Angelita Hunter
Court Supervisor

“In my role at DSHS, I have three areas of focus: transition to adulthood, medical home, and community inclusion. The area that most interests me is inclusion. This reaches from school, to workplaces, to community spaces and events, and everywhere in between. I believe this program will help me be more knowledgeable and effective in my role.”

Cassandra Johnson
Program Specialist V



“ I want to better understand the needs of individuals receiving services from HHSC and the needs of their families.”

Elaine Wied
Program Specialist



“I wanted to meet others who see the need to increase outreach to school districts in an effort to educate and provide families with the resources they need for their loved ones before it’s too late. I am passionate about tackling these issues in rural areas, particularly those that fall below the poverty line where families so often are without the information and support they need. Families shouldn’t have to spend countless hours searching for answers in a confusing and muddled system.”

Hannah Roundtree
IDD Crisis Stabilization Specialist

2020 CLASS

THE ARC OF TEXAS 2020 PARTNERS IN DISABILITY LEADERSHIP



“The Partners in Disability Leadership mission statement said it all, as I want to ‘impact positive change in the services and support systems used by Texans with IDD and their families.’ I see this program as an exciting opportunity to learn from and collaborate with others outside of HHSC in a meaningful way.”

Jennifer Chancellor-Hurd
Manager of the Long Term
Services and Supports (LTSS) Policy Unit
Medicaid & CHIP Services

“I work closely with stakeholders on Medicaid policy and program development to inform the system redesign for the IDD services and support as directed in Texas Government Code, Chapter 534. Developing partnerships and working collaboratively with other disability leader in Texas informs and strengthens systemic change.”

Joy Kearney
Medicaid Policy and Program-Senior Policy Advisor-IDD



“Currently, I work on a variety of different projects in policy and program development, PPD. I was fortunate to be selected as a participant in the PDL this year and look forward to the collaboration with others during the sessions. All of the information gained over the next six months will allow me to reflect upon my role and how I can continue to support others that are providing and/or receiving services.”

Jennifer Marshall
Program Specialist

“After eight years working in various roles within the Texas state government serving those with intellectual and developmental disabilities (IDD), I noticed there are many areas in which policy and processes related to state-funded services could be more disability friendly. I am passionate about educating myself on disability rights from a social justice perspective, so I can learn how to help make these spaces more affirming for those who must spend time in government space to receive services that they need.”

Erin Perez
Program Specialist IV



“I am driven to make a significant contribution to real change in public policy, and integrate person-centered thinking and planning across HHSC program services and supports. There is a need for people to identify with person-centered values, integrate skills, and provide person-centered interactions, which synergistically transform the system. The infrastructure, system, and policy and procedures must support the change needed.”

Phyllis Matthews
Long Term Services and Supports Policy Advisor
Policy and Program Development
Medicaid & CHIP Policy



“As a lifelong educator who has worked to support and advocate for students with special needs, I believe informed advocacy is necessary to assist children and adults with disabilities and special needs.”

Karlyn Keller, Ed.D.
Division Director, Special Education &
Student Solutions



“My career started by working with people with disabilities as a Service Coordinator. I am interested in increasing housing options and employment opportunities for all. I joined the Partners in Disability Leadership to learn and achieve this goal through community collaboration.”

Roger DeLeon
Community Relations



“Some of my biggest professional challenges have been to help implement legislation that profoundly affects Medicaid service for people with intellectual and developmental disabilities, including Community First Choice, managed care pilots, and the future transition of long-term supports and services for people with IDD to managed care. I also served as the manager over consumer-directed services policy, person-centered practices, Money Follows the Person, and the HCBS settings regulations, among other topics. I’m always seeking more education, experience, and opportunities to have a positive impact on Texans with disabilities.”

Jennie Costilow
Director, Policy and Program Development
Medicaid & CHIP Services



“I have worked with individuals with intellectual and developmental disabilities (IDD) for the past 10 years. I began my career as a case manager for the Community Living Assistance and Support Services (CLASS) waiver program and now develop policy for the CLASS, Deaf Blind with Multiple Disabilities (DBMD), Home and Community-based Services (HCS), Medically Dependent Children Program (MDCP), and Texas Home Living (TxHmL) waiver programs. I love being involved in the community and listening to what individuals have to say. This involvement impacts my ability to create policy to reflect their wants and needs. I participated in PDL to increase my awareness of disability rights and develop a foundation within my agency that listens to stakeholder feedback and creates a welcoming environment for individuals with IDD.”

Kendrah Buckley
Waiver Specialist



“I am interested in building connections between supports available in the IDD waivers, Medicaid Managed Care organizations, and other sources. I have over 20 years' experience building programs and processes at the state, 14 of those specific to Medicaid, and believe I can build on that experience to improve access to services for individuals with IDD.”

Jessica Morse
Director

THE ARC OF TEXAS
2020 PARTNERS IN DISABILITY LEADERSHIP



“I participated in PDL to expand my knowledge, collaborate and network with other leaders in the field of IDD, and to stay on top of the latest legislative developments that could impact the individuals we serve.”

Mendy Blank
Director of IDD

“I want to become a stronger, more effective advocate in assisting individuals with Intellectual and Developmental Disabilities (IDD), to have the best and most comprehensive supports possible. I would like to see more Person-Centered practices in all areas of services and supports that truly helps promote an individual’s independence. I also want to learn how I can contribute to improving IDD public policy, so there is an increase in funding for services and supports for individuals with IDD and to help to identify as well as remove barriers so individuals and their families have the best quality of life possible.”

Christopher Anderson
HCS Service Coordination Supervisor



“I am passionate about person-centered practices and believe this philosophy should be at the core of everything we do when working with people that receive services and their families. Unfortunately, health and safety are often the primary focus of a person’s support team when planning with someone who has an IDD diagnosis. Often, what is ‘important to’ the person is not truly considered or adequately included in their plan for services. As a participant of Partners in Disability Leadership, I want to become a better model for both staff and families on the importance of balancing both “important to” and ‘important for’ when working with individuals with IDD.”

Tina Carter
Quality Manager, IDD Services

2020 PDL SPEAKERS

“Let’s go out now and change the world! I expect big things to happen from you guys.”

Al Condeluci

“You will make a tangible difference in the lives of people with disabilities in Texas.”

Erin Lawler

I just want to remind you that all have the power to make a difference by sharing your story. I’m so proud of you. Congratulations!

Emily Ladau

“I thoroughly enjoyed our discussion on using plain language as a means to inclusion and I thank you for your continued service to Texans with disabilities.”

Dr. Miriam Williams

“Just remember: Change happens. It’s difficult, but if you’ve got a set of values and principles to guide you, you’ll know when compromise is OK and when it’s not.”

Bobby Silverstein

“I encourage you: Pursue what you are doing. Keep going. In the words of the late Justin Dart, a native of Texas, the father of the ADA: ‘Lead on.’”

Allan Bregman

“I want to just say how important your work is for the future of so many people in Texas, and thanks for making Texas a better and more inclusive place.”

Peter Leidy

“You have worked hard over the last several months. You’ve taken time away from your friends and your family, and your dedication will pay off. Partners in Disability Leadership is the gift that will continue to keep giving, not only in your work but in your commitment to the disability community. I will be looking forward to seeing your name in systems change in Texas. I know all of you are up to the challenge.”

Jane Dunham

“Our work isn’t done. Your work isn’t done. Stay true to your mission. Have a mission that people can believe in. Surround yourself with people who have likeminded values; strong partnerships. And don’t give up.”

Joseph MacBeth

“What’s past is past, there is more coming, and I feel like you are in unique circumstances to make a huge difference in achieving the kinds of outcomes that we all want.”

Dr. Michael Wehmeyer

Ari Ne’eman

Green Mountain Self-Advocates

Karen and Max

Mary Lou Bourne

HEARING HEUMANN

Civil rights leader, disability activist, and history-maker
Judy Heumann talks compromise, stress management,
perseverance, and Trevor Noah.

NOTE: ANSWERS HAVE BEEN EDITED SLIGHTLY FOR LENGTH AND CLARITY.

Judy Heumann skipped getting ice cream. It was a mild November day in Washington, DC, and Former Vice President Joe Biden had been declared the winner of the 2020 Presidential Election earlier in the day. Heumann, who served in both the Clinton and Obama administrations, had a prime location to hear the celebration happening in the DC streets. Although Heumann's husband suggested ice cream as a celebratory treat, Heumann instead tuned in virtually to the 2020 Partners in Disability Leadership graduation ceremony.

The honking and cheering happening outside Heumann's window only added to the excitement of her conversation with The Arc of Texas Deputy Director of Public Policy & Advocacy Ashley Ford. Heumann answered questions from graduates, sharing her thoughts on compromise, being called a "badass" by *The Daily Show* host Trevor Noah, and more. Read on for takeaways from her conversation.

ON COMPROMISE

JUDY HEUMANN: Life is compromise. ... You have to have compromise, but you need to know what you want, because otherwise your compromising won't be good.

When we were working on the ADA, one of the issues that I had been not happy about from the very beginning was [precluding personal assistance services.] Many of the people you work directly with or helping to support in one way or another may also need support at work. Some people may need help getting

"You have to compromise, but you need to know what you want, because otherwise your compromising won't be good."

- JUDY HEUMANN

their coat on and off, or going to the bathroom, or feeding themselves. That was explicitly precluded in the ADA. Explicit language that said, the employer does not have to help you get your coat on and off, does not have to help go to the bathroom, does not have to help them eat. I fought really hard on that. There's a really small percentage of us who need one of those supports.

What are you willing to compromise on? ... What do we believe the "A plan" should look like? And when you're compromising, if it's possible, to understand what the implications of that compromise will be. I think you should always have a game plan that people can agree with, that in the event that this doesn't happen, whether it's right or wrong, this is what the fallback positions are.

ON OVERCOMING GENDER BARRIERS

HEUMANN: You never call a man assertive, right? They call women assertive because we are stepping out of our prescribed circle. It's something that I had to learn as I got older and as I



got more comfortable in using my own voice. ... There are many ways to be assertive. You can do it in how you say it, in your writing ... I don't think we should look at only one way of being assertive. We have to teach young women and young boys about the issue of equality.

ON HER TREVOR NOAH INTERVIEW

TREVOR NOAH: *It feels like that's been the story of your life, though. Defiantly, you know, reminding people or even exposing to people how many obstacles so many people in our society face. You know, as an able-bodied person, I take so many things for granted.*

JUDY HEUMANN: *I call you "non-disabled," actually.*

NOAH: *You call me "non-disabled"? Oh. I never know which term it is, to be honest, because in the book ...*

HEUMANN: *I call you "non-disabled" because we also, um ... Because the likelihood of you acquiring a disability, uh, temporarily or permanently, is statistically very high, so ...*

NOAH: *Did you just threaten me?*

HEUMANN: When he said that [able-bodied person], I thought, I gotta say something. ... But, really, because his response was a very telling response, which is that an average person feels like acquiring a disability is a threat.

So, that word that he used, I talk about it, because he didn't mean it in a negative way, per

say, but clearly it was a visceral response that I think most people have. So, when you think about acquiring a disability as a threat, then I think it also impacts the way you relate to people. I think these are fundamental issues that we don't talk about a lot, but [we are] trying to change the way we as a society react.

ON MANAGING STRESS

HEUMANN: It's very important I think—right now in particular with COVID—we really more consciously look at this issue, because it's not just burnout from work, but there are many more aspects of burnout among our families. .. I think obviously it's really looking at ways of getting outside, going for a walk, having someone, some people you can talk to, and really looking at ways of letting off pressure. ... Making time and trying to figure out how to create spaces for being introspective is really important, and a work in progress for me.

ON DISABILITY POLICY PROFESSIONALS AND ALLYSHIP

HEUMANN: There are some people who do their job every day: they have to make five widgets; they make five widgets. My presumption is that you're not people who want to make five widgets. You wouldn't be in the program if ... you didn't feel some investment in wanting to make things better. ... I also presume that it's more global. That you want to be able to have an impact and get a better outcome. A better outcome means that people you're working with can get things in a more timely way, and in a better way.



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