YOUR VOICE MATTERS IN POLICY AND PRACTICE

J. MICHAEL GRIFFIN & RYOKO YAMAGUCHI

…As It Relates to Persons with Neurodiversity in Post-Secondary Education

PRESENTATION AGENDA

- Introduction

- The "What" and "Why" of lived experience and personal narratives

- Case study: Neurodiversity in postsecondary education

- The "How" of lived experience: Your turn to try it out

- Wrap-up

INTRODUCTION

RYOKO YAMAGUCHI

WHO WE ARE

J. Michael Griffin

- **President** of Integrated Veteran Services & Consulting
    - Ed.D., Argosy University (Higher Post-Secondary Education & Psychiatric Rehabilitation)
    - Ed.S., Troy State University & University of Sarasota
    - B.S., Troy State University & Columbus State University (Human Services & Psychology and Education)
- **Curriculum & Program Designer** for individuals in the early stages of recovery, CDL license curriculum for English Learners, English Learner transition program into mainstream class, Theatrical Arts for the Deaf

Ryoko Yamaguchi

- **Vice President** of Integrated Veteran Services & Consulting
    - Ph.D., M.A., University of Michigan (Education & Psychology)
    - B.S.Ed., Loyola University in Chicago (Special Education, Psychology)
- **Social Scientist** specializing in at-risk youth behaviors, social emotional learning, and academic achievement
- **Special Education Teacher** (certified in Behavior disorders, Learning disabilities) taught in psychiatric hospitals, residential programs, and detention facilities.
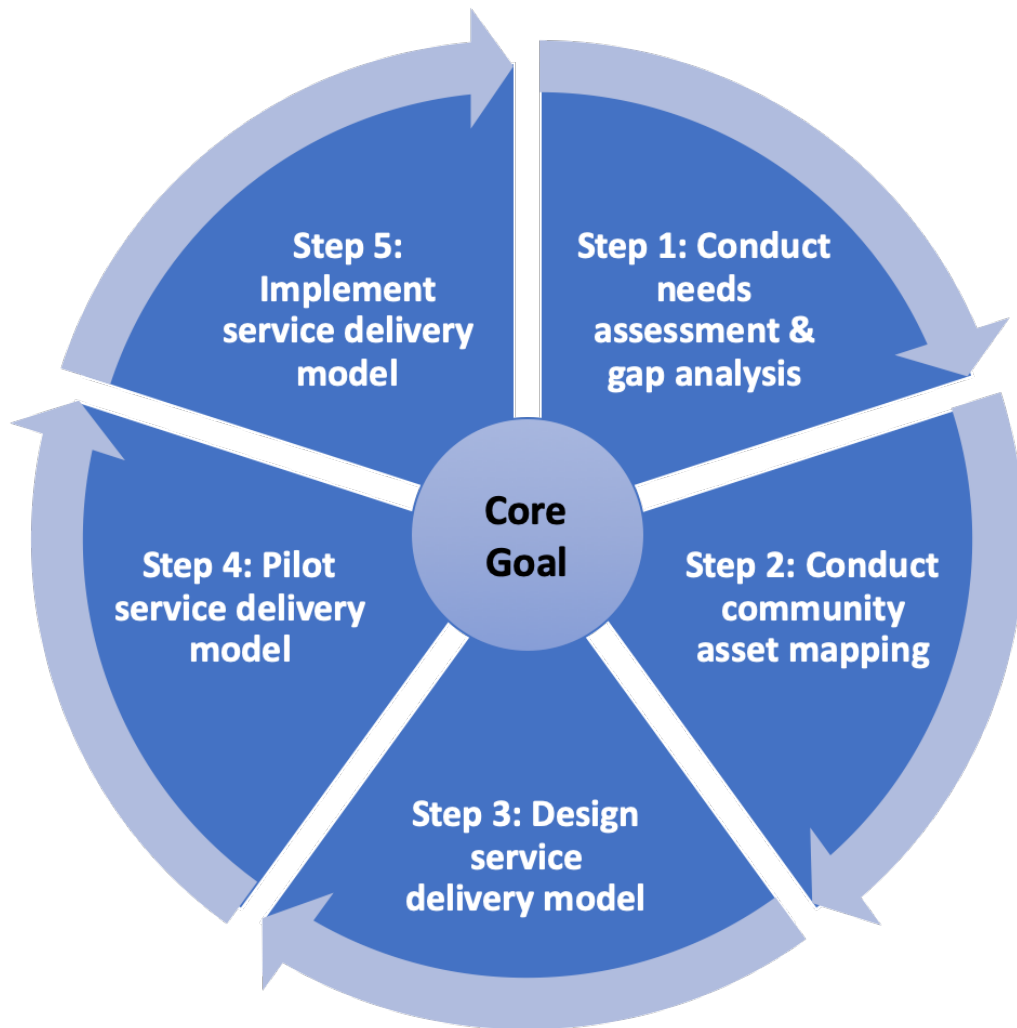
GOALS FOR TODAY'S SESSION

- **Learning Target 1**: Learn about how lived experience and personal narratives as data can help inform and improve policy and practice

- **Learning Target 2:** Practice how to use your own personal narrative as data to improve policy and practice

OUR FRAMEWORK: HARNESSING LIVED EXPERIENCE TO DEVELOP PROGRAMS, POLICIES, AND PRACTICE

Framework to Harness Lived Experience:

1. Core goal
2. Needs assessment and gap analysis
3. Asset mapping
4. Design
5. Pilot
6. Implement

Adapted: Yamaguchi et al (2017). *Adaptive Implementation: Navigating the School Improvement Landscape.* Lanham, MD: Rowman & Littlefield.

THE "WHAT" AND "WHY" OF LIVED EXPERIENCES AND PERSONAL NARRATIVES

RYOKO YAMAGUCHI

THE FALLACY OF OBJECTIVITY (OTHER PEOPLE'S NARRATIVES): EXAMPLE 1… THINGS THAT MAKE YOU GO "HMMM"

Results:

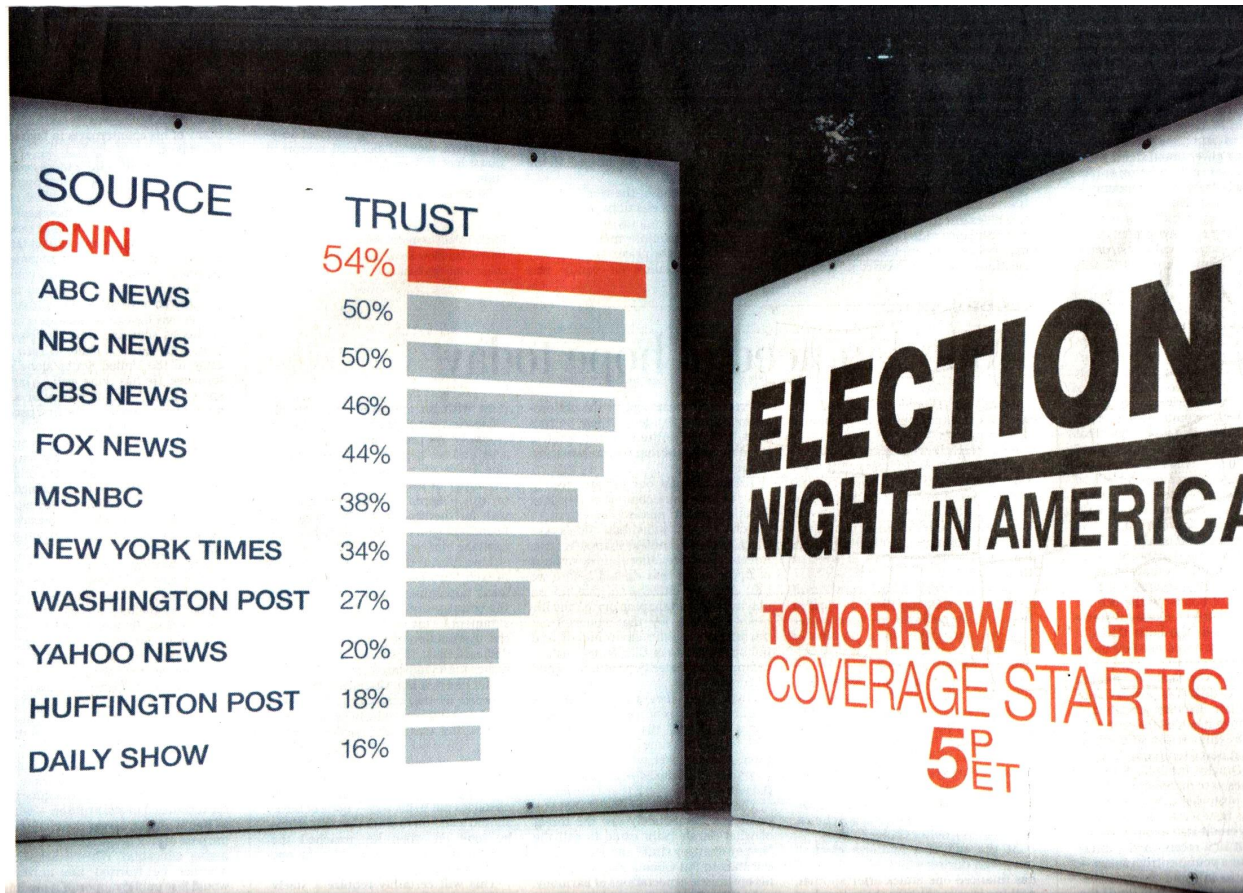- 80% of dentists recommend Trident compared to what? No gum? Other gum? Other candy?

Methodology:

- Who were the five dentists surveyed?

- How were they selected and surveyed?

- Do dentists recommend gum chewing?

- Do they themselves chew gum?

- Do they chew Trident?

- Did they get paid by Trident?

THE FALLACY OF OBJECTIVITY (OTHER PEOPLE'S NARRATIVES): EXAMPLE 2

THE FALLACY OF OBJECTIVITY (OTHER PEOPLE'S NARRATIVES): EXAMPLE 2 … THINGS THAT MAKE YOU GO "HMMM"

Results:

- There's barely any difference between CNN (54%) and ABC News (50%) or NBC News (50%)

Methodology:

- Who were surveyed?

- How many were surveyed?

- How were they selected and surveyed?

- Do they get the news on TV? On Internet? On paper?

- Did they get paid by CNN?

THE FALLACY OF OBJECTIVITY (OTHER PEOPLE'S NARRATIVES): HOW IT IMPACTS POLICY AND PRACTICE

Research Traditions …

- Positivist versus Constructivist
- Quantitative versus Qualitative
- Etic versus Emic
- External validity versus Internal validity
- Type I error versus Type II error
- Frequentist versus Bayesian

… Are Still Biased

- Researcher hypotheses
- Researcher assumptions (of data)
- Researcher "fishing" for results
- Researcher "slice and dice" for results
- Researcher interpretation of data and results

THE POWER OF LIVED EXPERIENCES (YOUR NARRATIVE)

- **Your lived experience and personal narrative can:**
  - Act as inspiration or muse for your work
  - Act as face-validity for your work
  - Act as data for your work

- **Influence and improve policy and practice:**
  - For underrepresented populations
  - To provide solutions to societal problems and challenges
  - To help organizations provide needed accommodations/services

THIS SOUNDS FAMILIAR…
HAVEN'T I SEEN THIS BEFORE?

- Psychology
- Physics
- Education
- Literature
- Law
- Entrepreneurship
- Policy

- Jean Piaget
- Newton
- IDEA/ PL 94-142
- TRR Tolkien, CS Lewis
- Ruth Bader Ginsburg
- Madam C.J. Walker to Carol's Daughter
- Civil Rights Act (1964, 1968), Title IX

RYOKO'S LIVED EXPERIENCE AS A MOM INFORMING POLICY

- **School District Policy for Course Request Forms (CRFs)**

  - CRF policy changed to not require teacher recommendation for course selection. Lauded as opening up access.

  - Data still shows achievement gaps between White and Black students, severe disproportionality of White students in gifted programs, advanced-level classes, and severe disproportionality of students of color in SPED, suspensions, remedial classes.

- **Lived Experience**

  - Denied advanced-level course recommendation from teacher

  - Two months of back-forth with counselors and **3** different course schedules to get it fixed

CASE STUDY: NEURODIVERSITY IN POSTSECONDARY EDUCATION

J. MICHAEL GRIFFIN

MICHAEL'S LIVED EXPERIENCE AS A STUDENT INFORMING POLICY

Why this study?

- Students with neurodiversities and nonvisible disabilities constitute the **largest subgroup** in postsecondary education (Blech, 2011)

- There is very **limited research** on the college campus experiences for these individuals, and on the educational trajectory of these students (Murray, 2017)

- Current researchers suggest institutions are **failing** to meet the needs of this subculture and address the downward attrition spiral with this population of students (Andrade, 2015; O'Shea, 2016).

RESEARCH QUESTIONS: USING LIVED EXPERIENCE

Not every disability is Visible.

Life Skills Village (n.d.)

Research Question: How does my experience in the college and post-secondary education culture, and subculture, with neurodiversity/ nonvisible disabilities connect with and offer insights about the culture of college program completion for students with nonvisible disabilities?

- What is the nature or essence of difficulties experienced when completing programs in postsecondary education with a neurodiversity-nonvisible disability?

- What phenomena contribute to the high attrition rate of college students with invisible disabilities?

- Does a lack of self-identification of a disability produce barriers that impede the progression of a college student with a nonvisible disability?

AUTOETHNOGRAPHY: A METHOD TO STUDY LIVED EXPERIENCE AND PERSONAL NARRATIVE

Data collection
- Audio-recording of self-reflection, self-observation, personal memory, writing on my own lived-experience, external data (emails, celebratory moments, etc.)

Data analysis
- Retrospective analysis, introspective analysis, triangulation of multiple sources of data

Data synthesis
- A survey instrument was utilized in maintaining the focus of the research questions and to extract the data from the lived experience

IMPLICATIONS FOR POLICY AND PRACTICE

Study Findings

- Support using all data/document sources that provide freedom for personal creativity of an individual's voice as evidence that drives a more efficient system of college accommodations and student support services.

- Fuel the existing self-directed care movement, inspire hope in students with nonvisible disabilities to embrace the belief in *self* and the ability to flourish in personal goal orientation.

- Help to educate readers, equip and/or influence policy makers, and higher education staff as well as give insight into existing procedural/programs model, current student accommodations, and support services.

- Provide a greater perception into the life or lives of students with nonvisible disabilities; thereby, helping to shape or reshaping cultural views of this population and inspire greater empathy for the educational aspirations of this subculture in higher education (Zabonick, 2013).

- Add to current research and knowledge on this subject, and may be used in support of counternarratives on best practice for students with nonvisible disabilities.

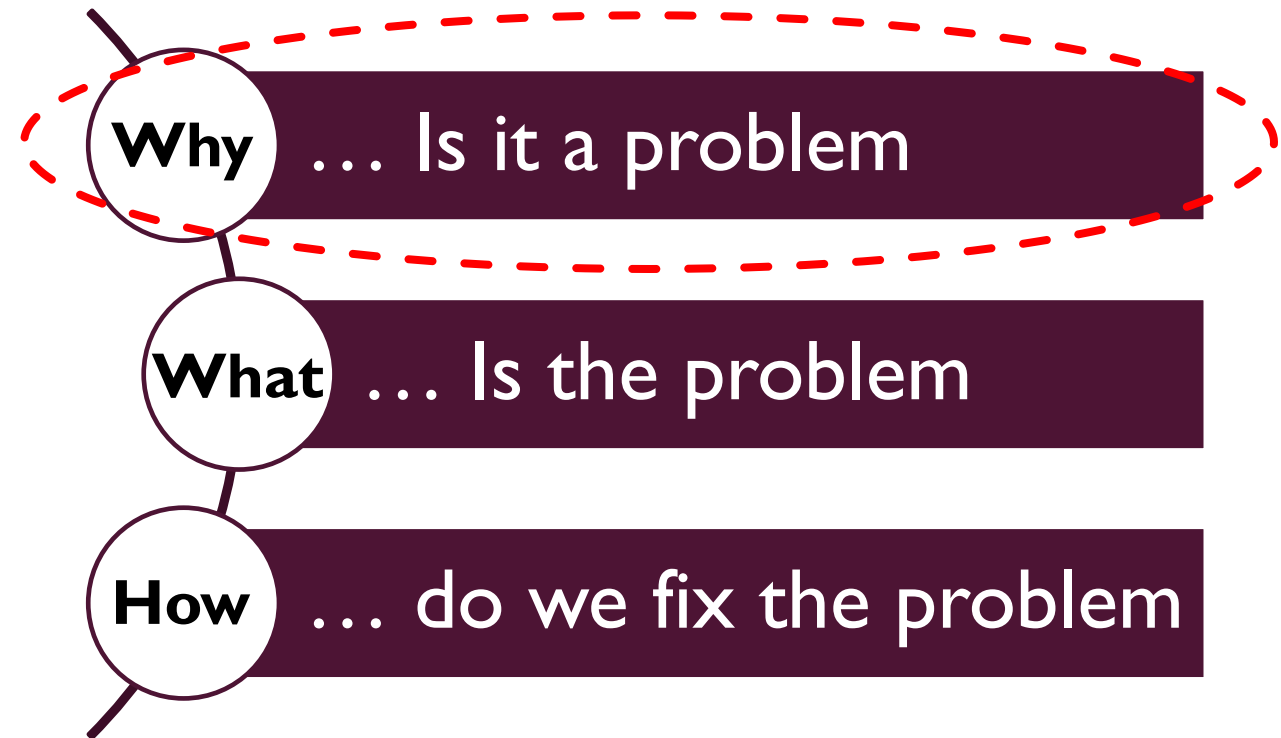# THE "HOW" OF LIVED EXPERIENCE: YOUR TURN TO TRY IT OUT

RYOKO YAMAGUCHI AND J. MICHAEL GRIFFIN

GETTING TO KNOW THE PROBLEM

In policy and practice:

- Tendency to go straight to the WHAT and HOW

- Spend time to understand the WHY

Why … Is it a problem

What … Is the problem

How … do we fix the problem

FIND YOUR NEW BEST FRIEND… GROUP INTO TOPICAL THEMES:

Topic 1: Employment

Lived experience:
- ❑ In my lifetime, I have experienced the effects of under-employment.
- ❑ In my lifetime, I have had jobs that paid less than minimum wage.
- ❑ I am a veteran who has experienced under-employment.

Topic 2: Housing

Lived experience:
- ❑ In my lifetime, I have experienced instability in housing.
- ❑ In my lifetime, I have struggled to find affordable housing.
- ❑ I am a veteran who has experienced housing instability.

Topic 3: Education

Lived experience:
- ❑ In my lifetime, I have experienced the effects of lack of education.
- ❑ In my lifetime, I have not had supports/ accommodations to do well in school.
- ❑ I am a veteran who has experienced inequities in schooling.

DISCUSS AND DRAFT: PROBLEM STATEMENT AND CORE GOAL

- **Probing questions to identify problem**
  - Why do you think it's a problem?
  - Who does this problem affect? Who does this problem benefit?
  - How do you know it is a problem?
  - What needs to be in place to improve the problem?
- **Given problem, create a core goal**
  - Turn the problem statement into a core goal or mission
  - Example core goals:
    - Increase number of students of color who graduate high school college-ready
    - Improve culture of college program completion for students with nonvisible disabilities
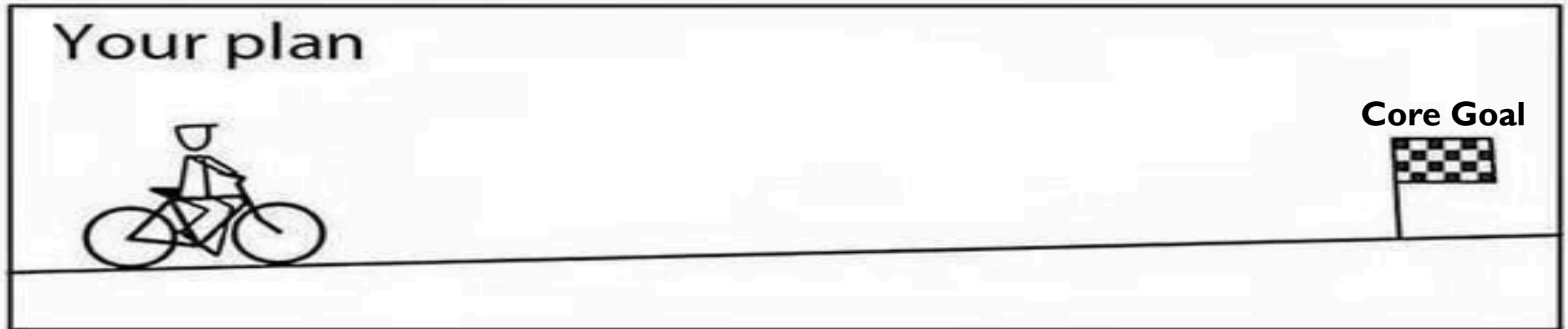
SHARE-OUT 1: PROBLEM STATEMENT AND CORE GOAL

- What is your **problem statement** given your lived experience?

- What is your **core goal** given your lived experience?

Questions or Comments?

NOW THAT I HAVE A CORE GOAL, NOW WHAT?
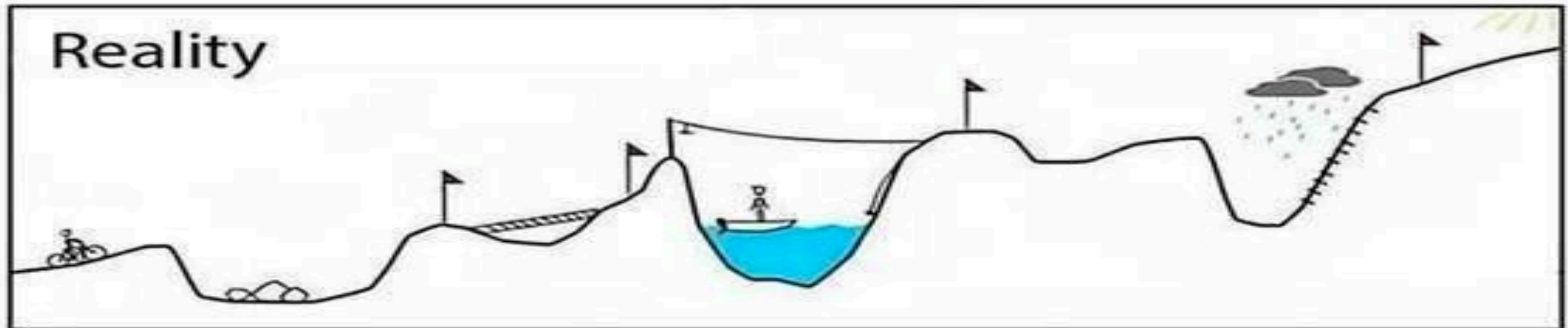
What's for Dinner?

OUR CORE GOAL

Make healthy meals for the family

HANGRY KID ALERT!

Here's my situation
(Need and gaps)

Here's what I have
(Assets)

The EatingWell Taco
★★★★⯪

🕐 Cook 55 m | Ready In 1 h 15 m

Recipe By: EatingWell Test Kitchen

"Building the perfect taco is a very personal task—cheese under meat, cheese on top, no cheese at all? This is just our recommendation."

Ingredients

• 12 6-inch corn tortillas
• Canola oil cooking spray
• ¾ teaspoon chili powder, divided
• ¼ teaspoon salt, divided
• 8 ounces 93%-lean ground beef
• 8 ounces 99%-lean ground turkey breast
• ½ cup chopped onion
• 1 10-ounce can diced tomatoes with green chiles, preferably Rotel brand (see Tip), or 1¼ cups petite-diced tomatoes

• ½ teaspoon ground cumin
• ½ teaspoon ground chipotle chile or 1 teaspoon chili powder
• ½ teaspoon dried oregano
• 3 cups shredded romaine lettuce
• ¾ cup shredded reduced-fat Cheddar cheese
• ¾ cup diced tomatoes
• ¾ cup prepared salsa
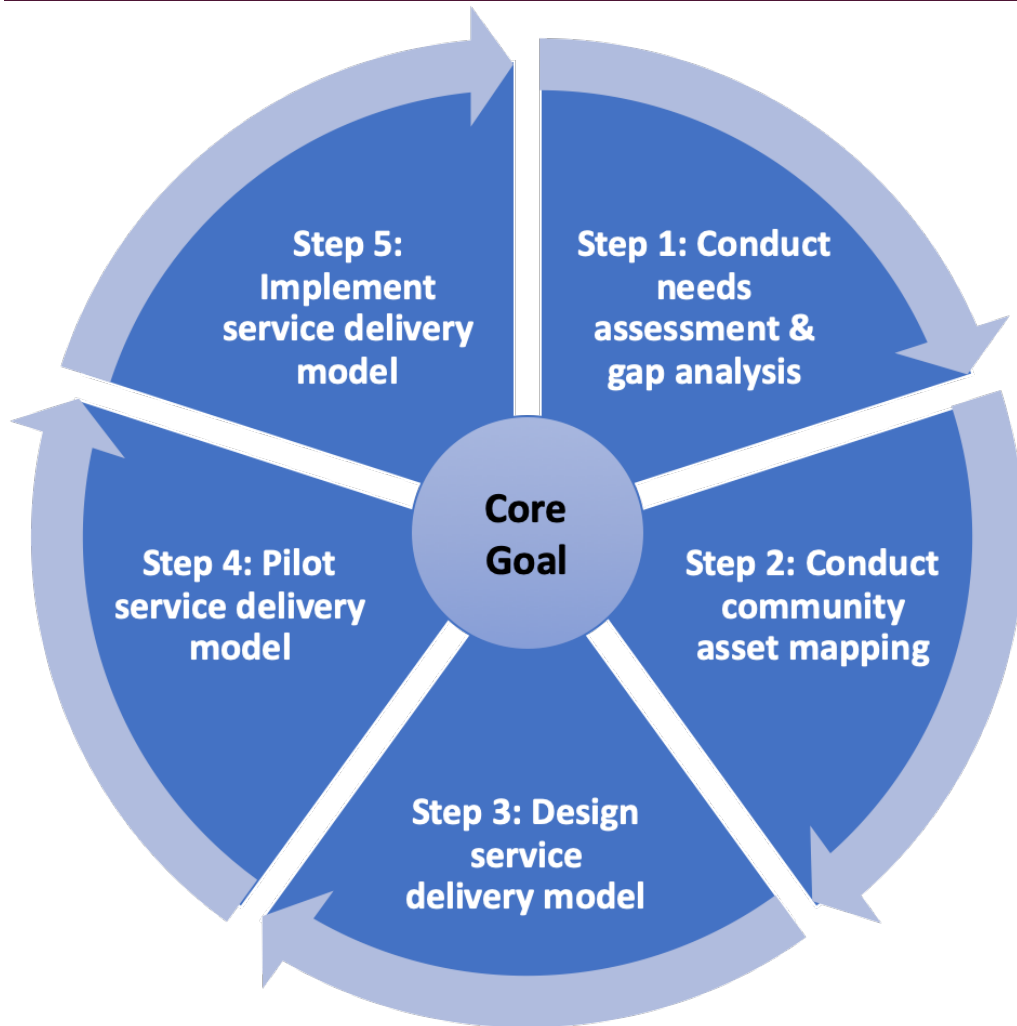
Here's my plan
(Design)

… Because this is my core goal.

My plan versus the reality was <u>**not**</u> the same.

# THE "HOW" OF LIVED EXPERIENCE TO IMPROVE POLICY AND PRACTICE

Framework to Harness Lived Experience:

1. Core goal
2. **Needs assessment and gap analysis**
3. **Asset mapping**
4. **Design**
5. Pilot
6. Implement

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DISCUSS AND DRAFT: NEEDS AND GAPS, ASSETS, DESIGN
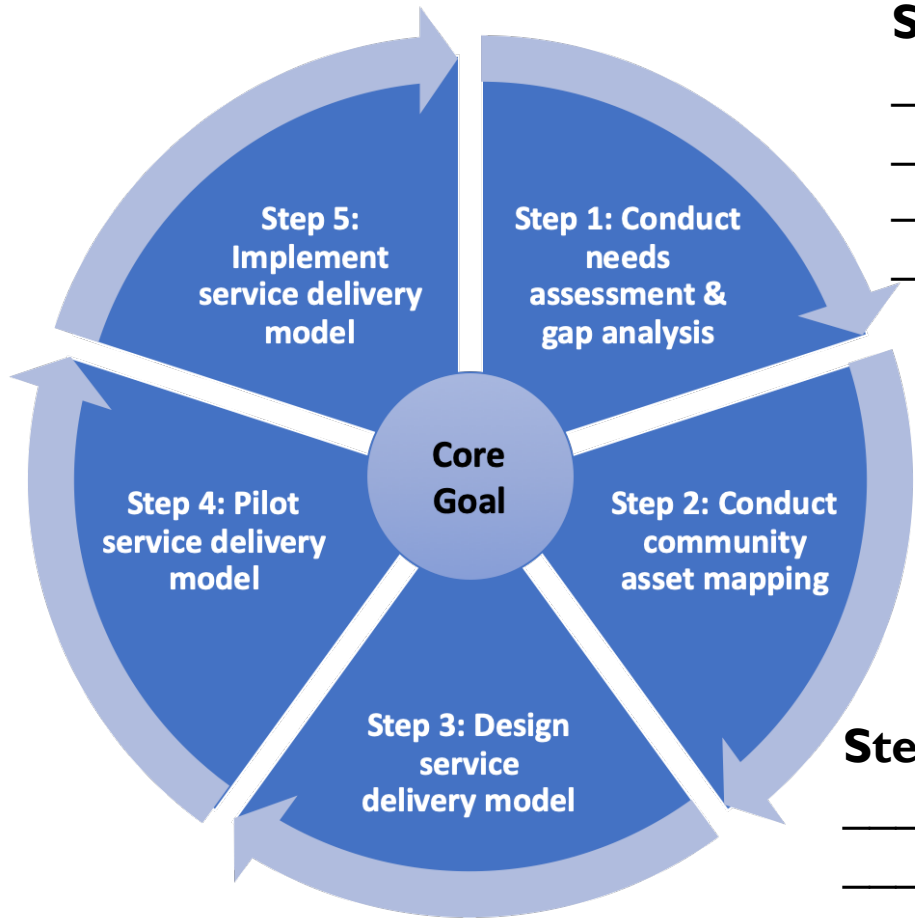
Step 1: Needs & Gaps

_____

_____

_____

_____

Step 2: Assets in Community

_____

_____

_____

_____

Step 3: Design Policy or Practice

_____

_____

_____

_____

SHARE-OUT 2: PRESENT YOUR DRAFT SOLUTION

Given the core goal…

- Needs and Gaps

- Community Assets

- Design (Plan) of Program, Policy or Practice

Questions or Comments?
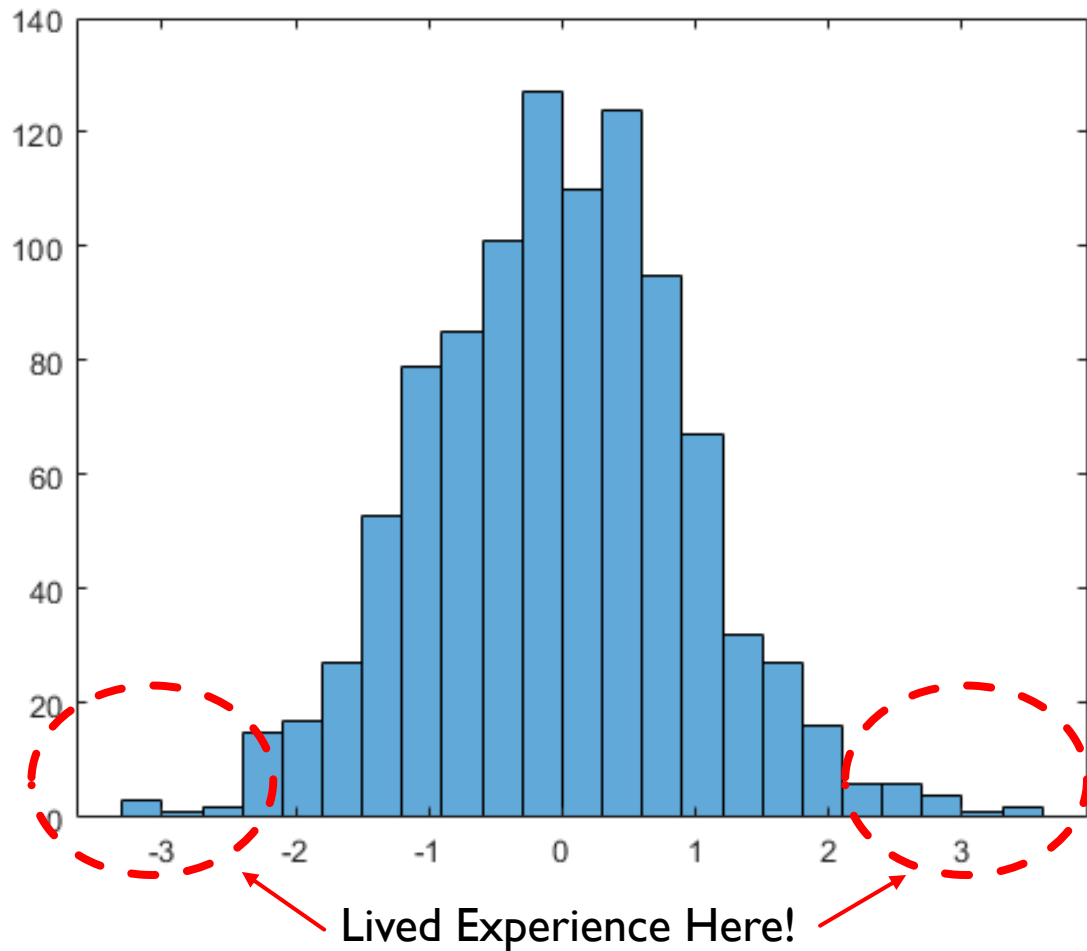
NEXT STEPS WOULD BE…

- Step 4: Pilot
  - Small scale implementation or pilot, similar to beta-testing
  - Learn from the data to improve the plan/ design
- Step 5: Implement
  - Implement at scale, but with continuous data loops to adapt and improve along the way

WRAP UP

HOW LIVED EXPERIENCE IMPROVES POLICY AND PRACTICE: VALUE OF OUTLIERS

Lived Experience Here!

- The story of outliers
- The story of best practices (Bright Spots)
- The story of challenges and lessons learned (What Not to Do)
- The story of the "real" problem and core goal

HOW LIVED EXPERIENCE IMPROVES POLICY AND PRACTICE: VALUE OF EXPERIENCED REALITY

Offers Services → Receives Services → Services Improve Outcomes

Lived Experience Here!
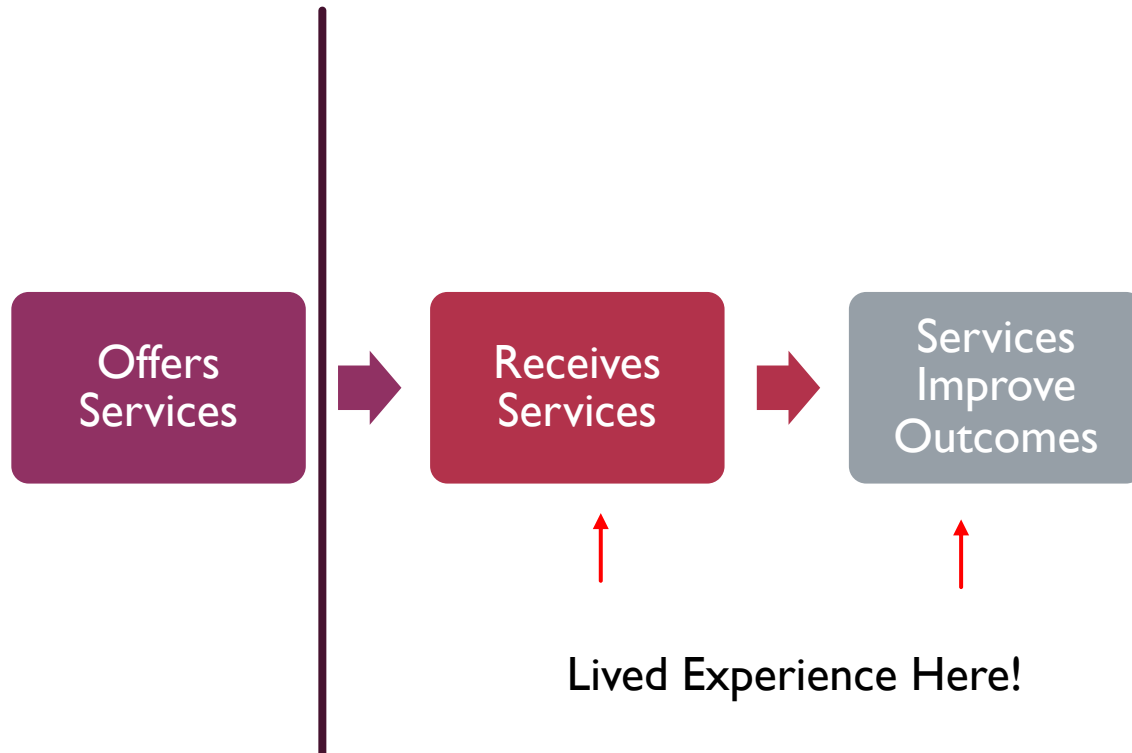
- The story of experienced reality (plan versus reality)
- The story of needs and gaps
- The story of receipt of services (offering versus receiving services)
- The story of what works or does not work (did it improve outcomes)

OUR FRAMEWORK: HARNESSING LIVED EXPERIENCE TO DEVELOP PROGRAMS, POLICIES, AND PRACTICE
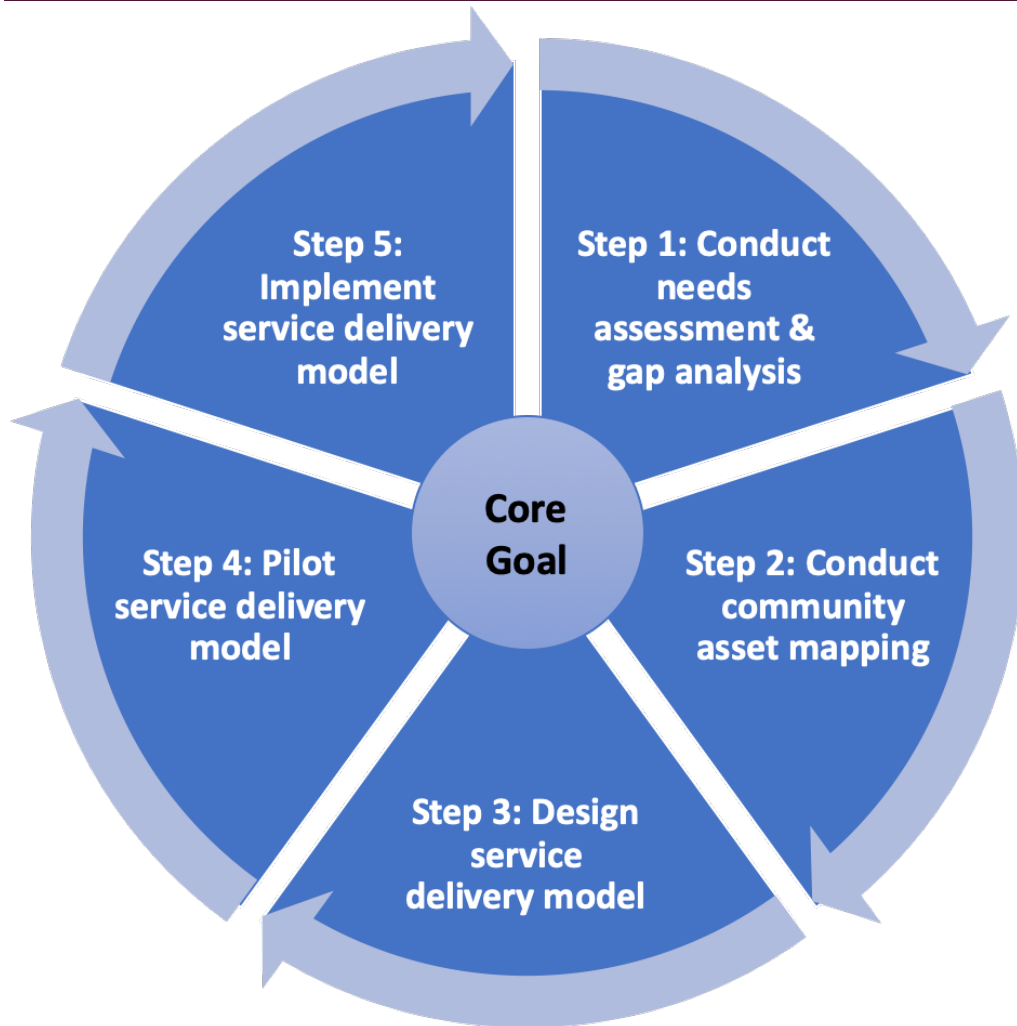
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FINAL TIPS

YOUR VOICE MATTERS IN POLICY AND PRACTICE

- **Your voice matters!**
  - Your voice can help at a larger scale to improve programs/policies/practice.

- **Speak up!**
  - Use your voice and experience throughout the program/policy/practice cycle.

- **Slow down!**
  - Use your voice and experience to focus on the problem statement and core goal.

Thank You!

Want to keep the conversation going?
Contact us!

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