2018 NATIONAL RYAN WHITE CONFERENCE ON HIV CARE & TREATMENT

# Disclosures

Paterson-Bergen-Passaic TGA, Dallas, TX Ryan White Planning Council and Iowa Department of Public Health have no financial interest to disclose.

Jesse Thomas works as Project Director for RDE System Support Group, LLC.

Nancy Erickson is principal of New Solutions Inc.

This continuing education activity is managed and accredited by Professional Education Services Group in cooperation with HSRA and LRG. PESG, HSRA, LRG and all accrediting organization do not support or endorse any product or service mentioned in this activity.

PESG, HRSA, and LRG staff has no financial interest to disclose.

# Introductions

Jesse Thomas, Project Director, RDE Systems

- Serving public health for over 20 years, HIV/AIDS programs 14+ years (HRSA, CDC, HUD, NIH)

- RDE Systems: First PLWHA IT company to do online consumer needs assessment surveys.

- Technical Manager for over 18 HRSA Special Projects of National Significance

# Learning Objectives

At the conclusion of this activity, the participant will be able to:

1. Recognize how a paradigm of **improved data collection** strengthens **grant applications**, provides answers to community planning bodies, illuminates **counterintuitive insights** important for the description of barriers and helps positively to influence health planning and policy recommendations

2. Describe how to **adopt and adapt strategies and tools** to deliver web-based technology to the community and planning bodies while overcoming digital divides and perceptions of digital divides.

3. Identify, analyze and evaluate the **challenges and benefits** of an innovative program for mobile / web-based, audio-assisted, multilingual Needs Assessments and Client Satisfaction Surveys.

# National HIV/AIDS Strategy

Goals:

1. Reducing new HIV infections

2. Increasing access to care and improving health outcomes for people living with HIV

3. Reducing HIV related disparities

(Implementation Plan: Achieving a more coordinated National response to the HIV/AIDS epidemic in the U.S.)

# How Do We Know What Services to Provide?
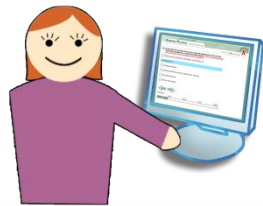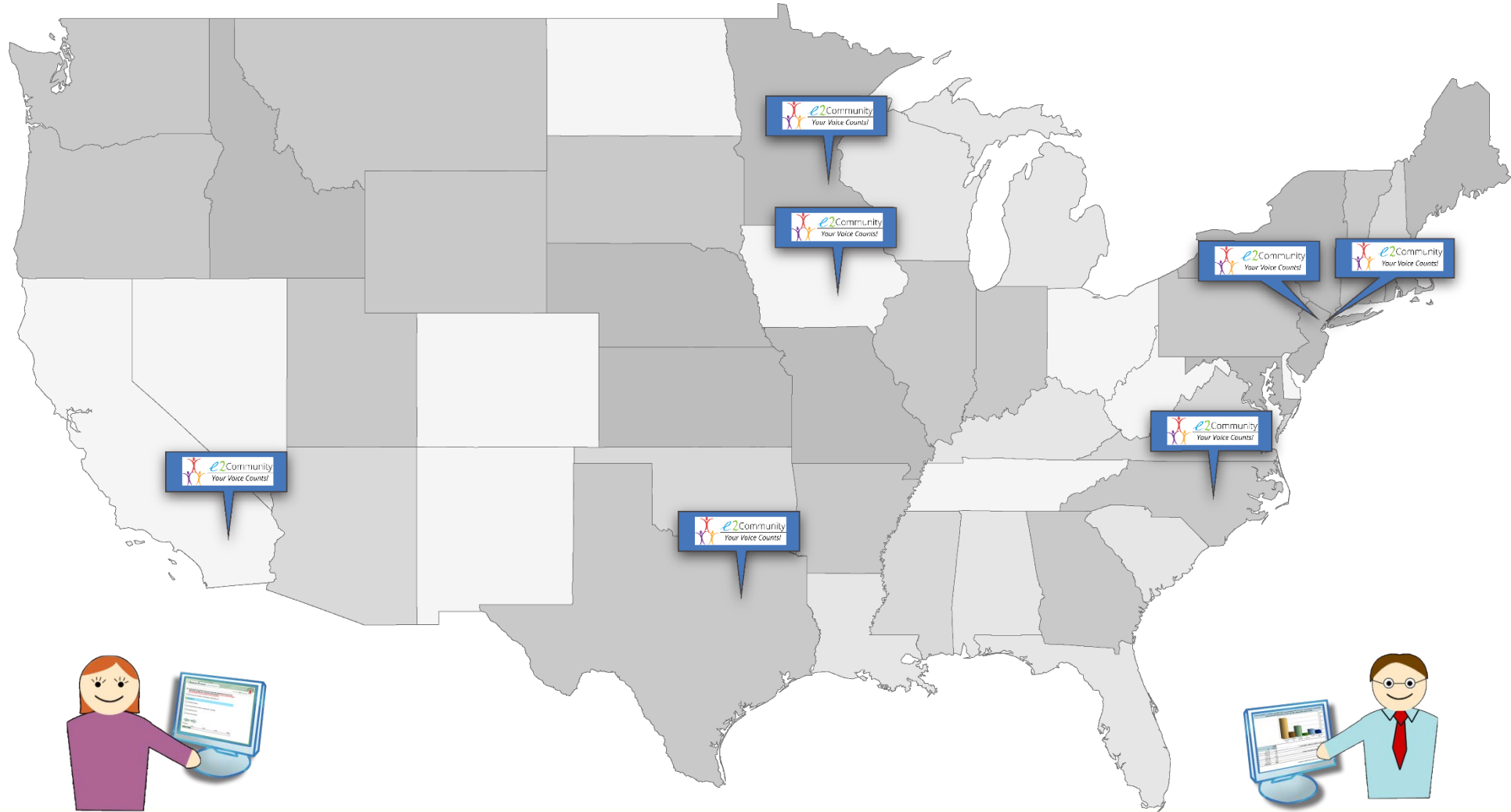
Evidence-based planning for HIV prevention and care services begins with:

**DATA-DRIVEN NEEDS ASSESSMENT**

The "Justification of Need" is included in every grant application that you write.

Developing an effective needs assessment process is vital to organizational sustainability and delivering high quality, effective programs.

# National Context

# Over 8,500 Total Consumers
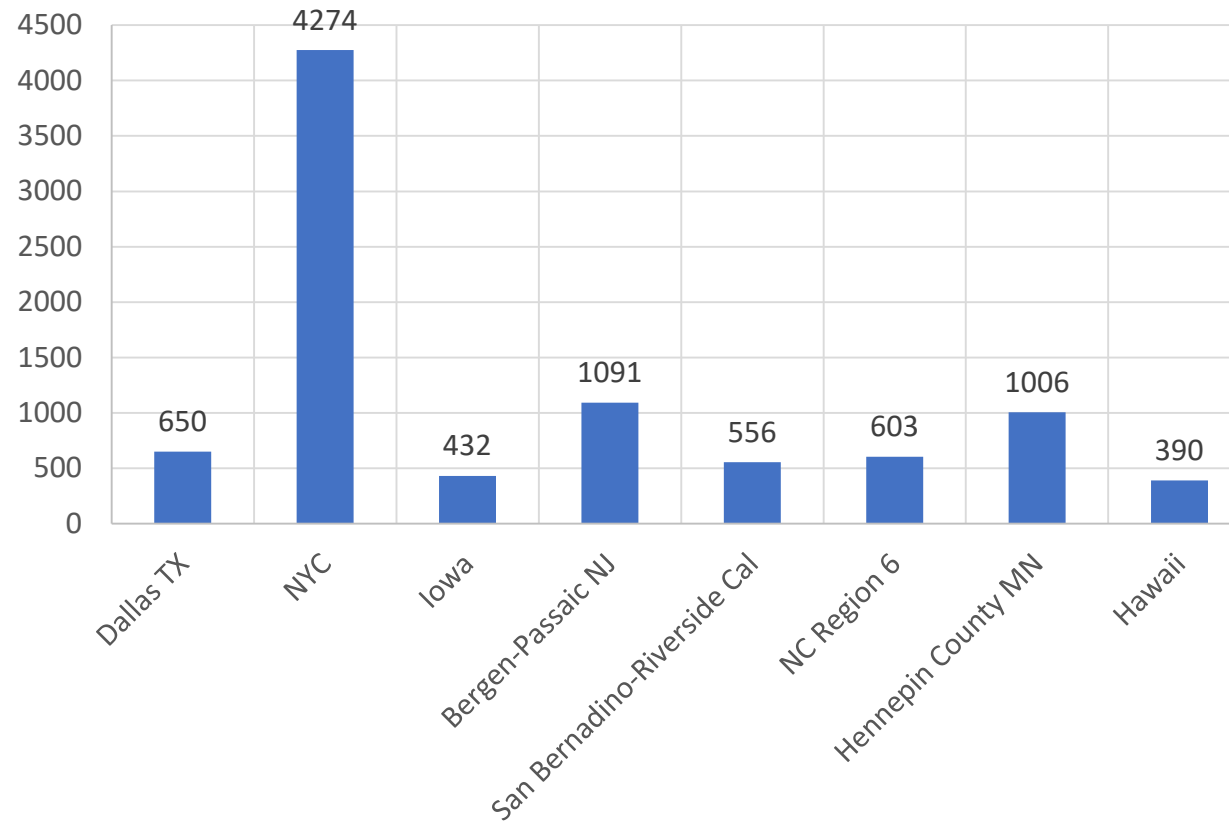
# Survey Complexity: Over 9,800 Q & A Fields



| Location | Value |
|---|---|
| Dallas TX | 1197 |
| NYC | 1166 |
| Iowa | 1257 |
| Bergen-Passaic NJ | 1598 |
| San Bernadino-Riverside Cal | 897 |
| NC Region 6 | 662 |
| Hennepin County MN | 1722 |
| Hawaii | 1314 |
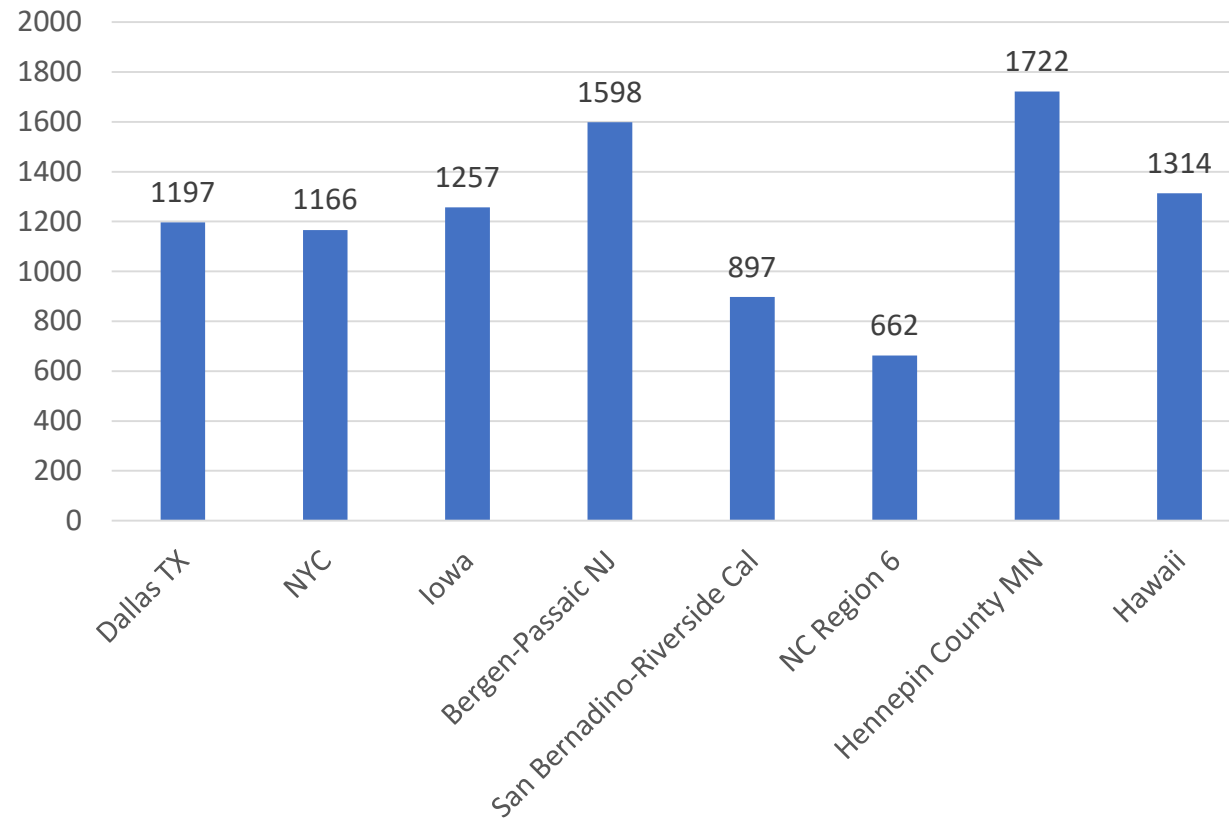
# Over 6 Million Data Points
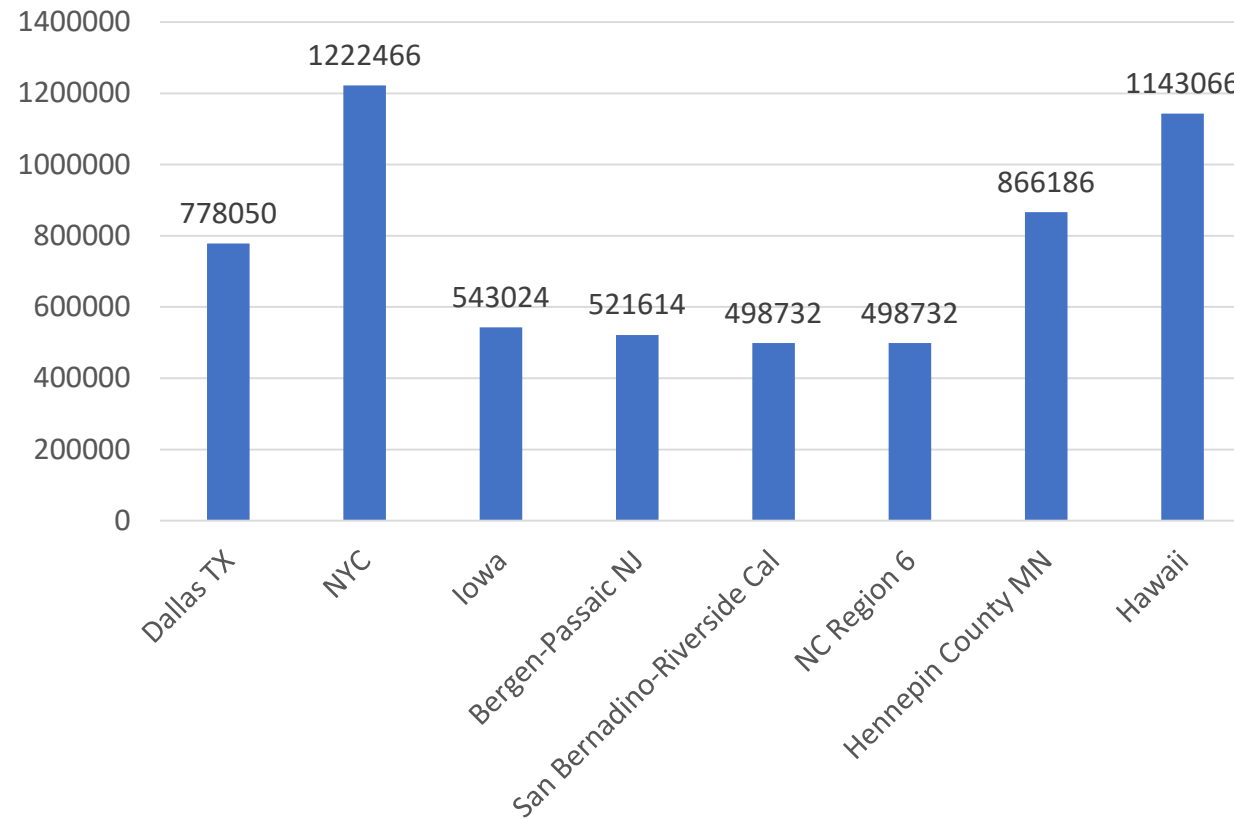
# Diversity of Size of Regions: PLHWA



| Region | PLHWA |
|---|---|
| Dallas TX | 19,389 |
| NYC | 119,550 |
| Iowa | 2,496 |
| Bergen-Passaic NJ | 4,286 |
| San Bernadino-Riverside Cal | 12,353 |
| NC Region 6 | 5,955 |
| Hennepin County MN | 4,420 |
| Hawaii | 2,519 |
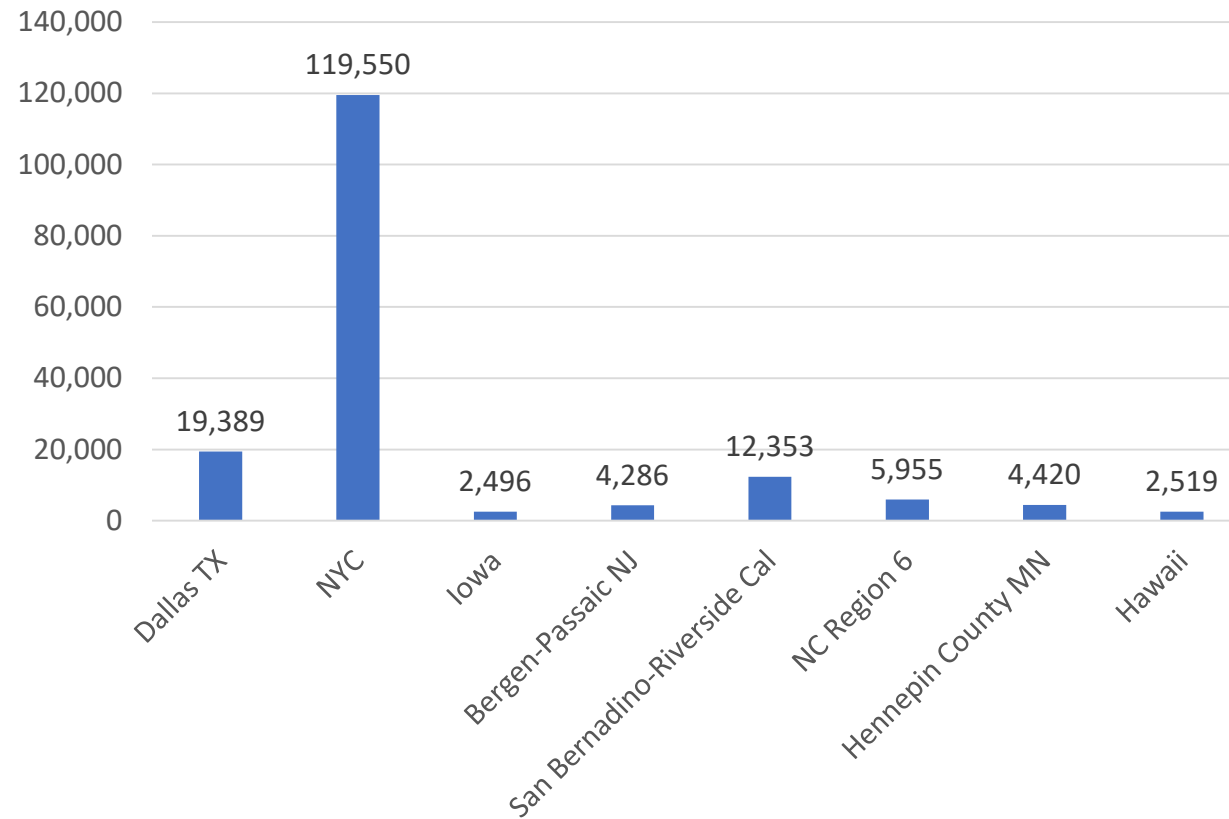
# Over $43,000 in Client Incentives Distributed

# Over 17,000 Staff Hours Saved!

# Traditional Needs Assessment Process

# Problem Statement

1. Too much time spent managing paperwork

2. Delay from data collection to action

3. Validating surveys a challenge

4. Too costly and inefficient

5. Paper reports are not interactive
   - Questions people have about the data result in health planners having to manually re-analyze the data

# Our Vision
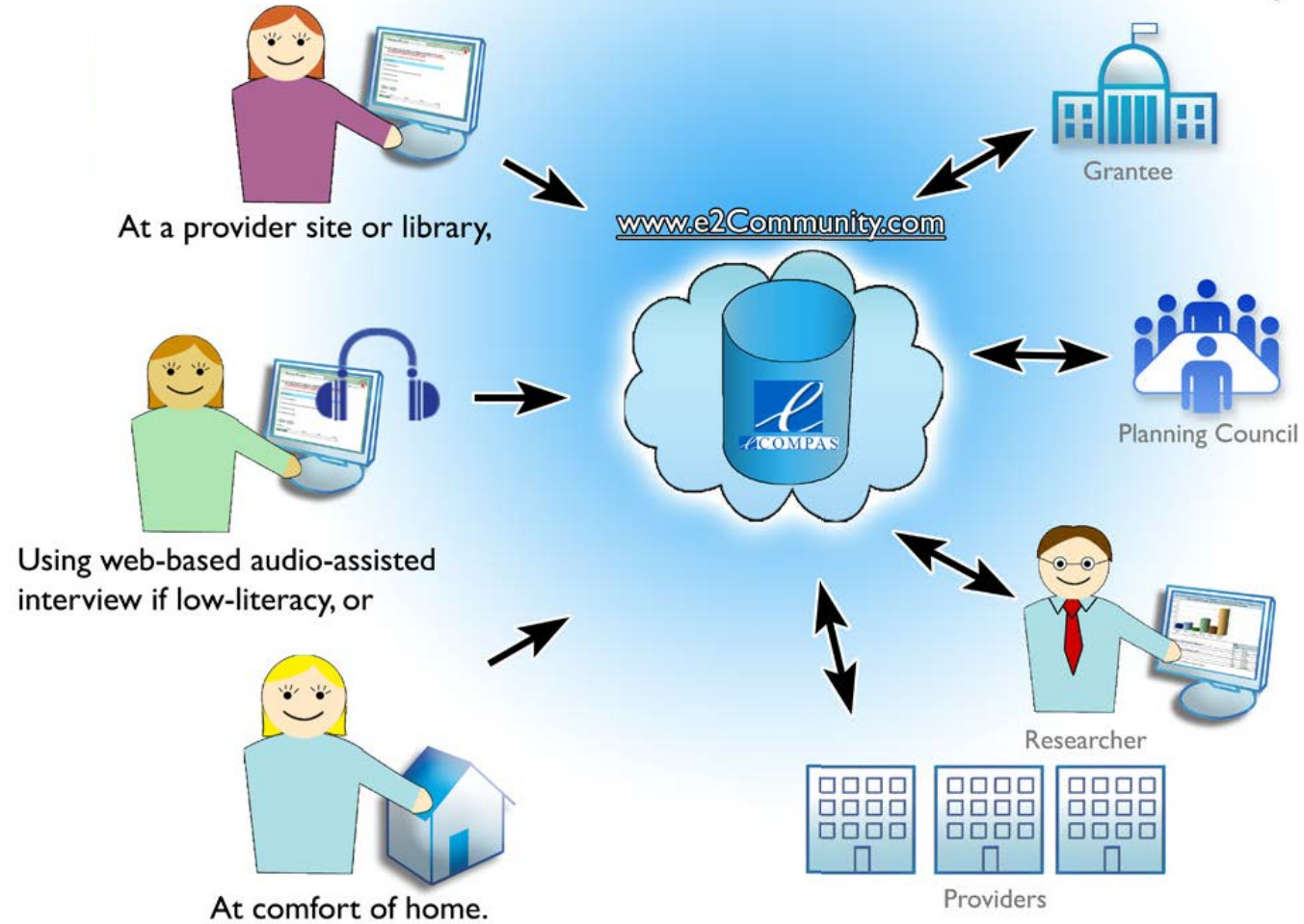
# BEFORE: Paper Interview Effort: Survey Wave & Reporting



Paper Interview Effort: Survey Wave & Reporting
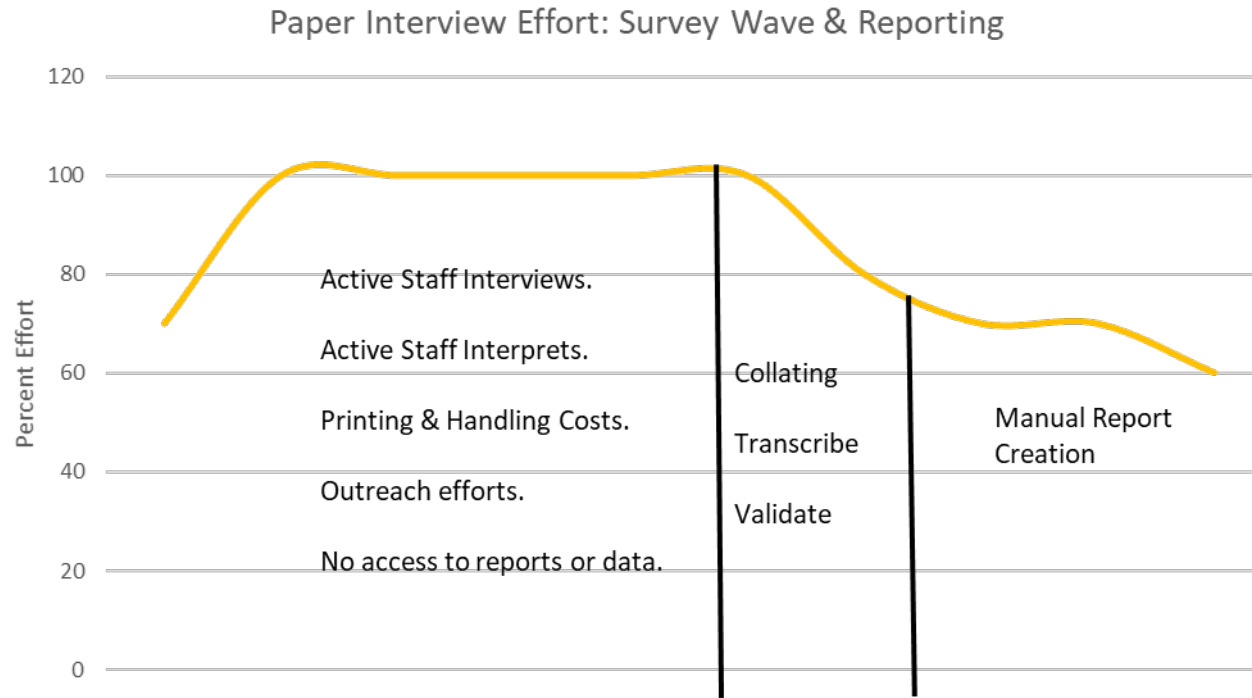
# AFTER: Much less effort + quicker survey cycles with Web (e2Community)



e2Community Effort: Survey Wave & Reporting

# Health Planning: A Tale of Two Eras



Percent Effort Over Months for Two Survey Waves

26. Answer each of the following questions, following directions listed under the headings.

**The Old Way**

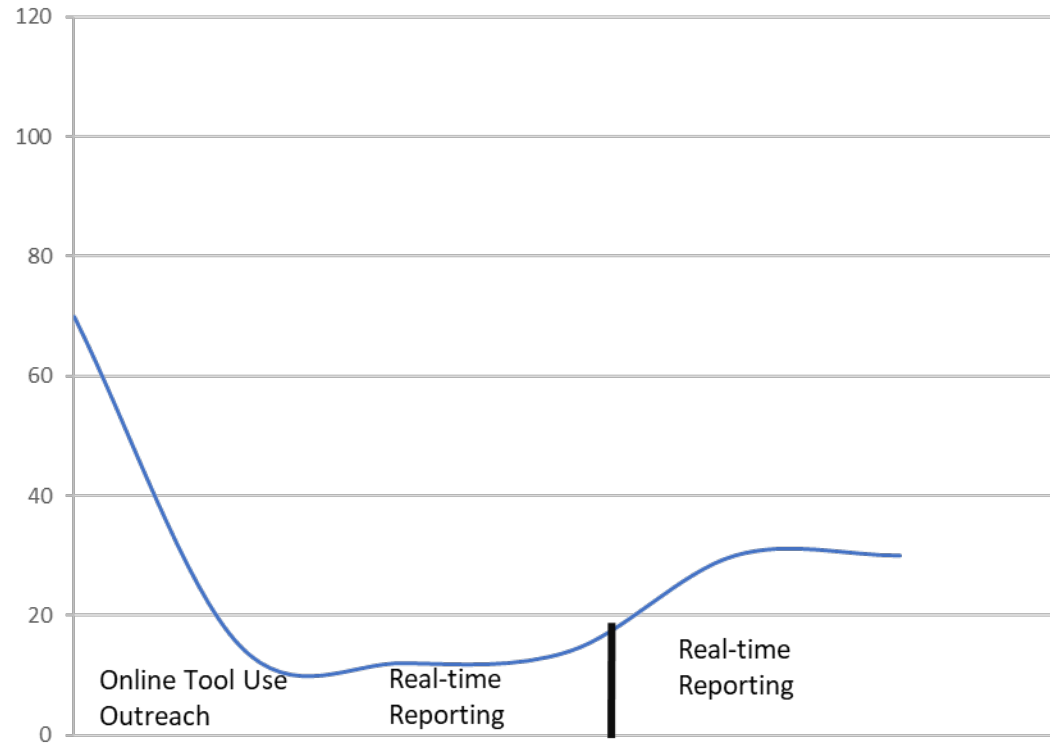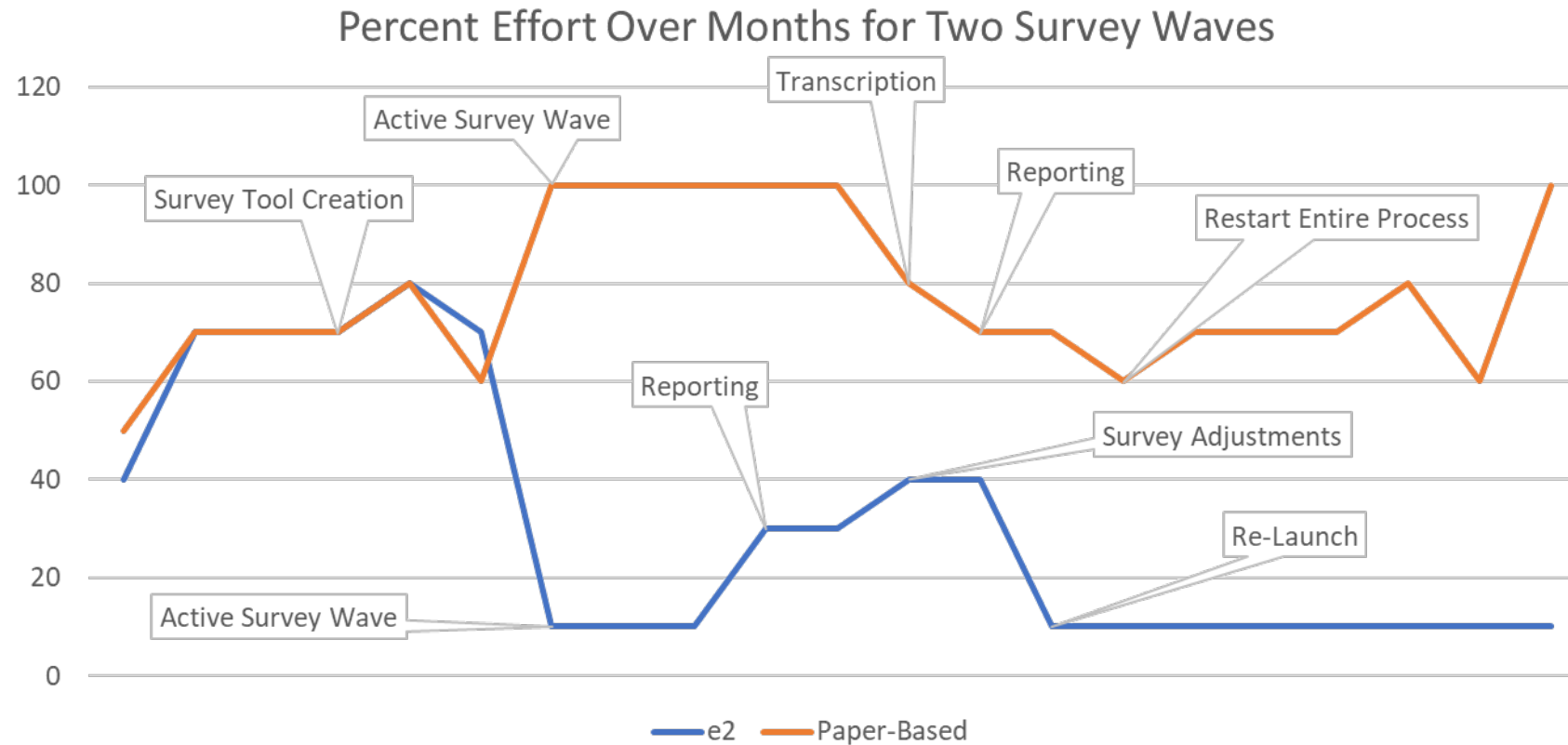| | A<br>During the past 12 months, did you *get*:<br><br>Yes = 1 *(Go to B)*<br>No = 2 *(Go to C)*<br>Refused = 3<br>Don't know = 4<br>*If 3 or 4 STOP. Go to next category.* | | | | B<br>If YES, how easy was it for you to get this service?<br><br>1= Easy<br>2= Somewhat hard<br>3= Hard<br>4= Have not used or tried to get<br>*If 1 or 4 STOP. Go to next category*<br>*If 2 or 3 , go to D* | | | | C<br>If NO, during the past 12 months, did you *need*?<br><br>Yes = 1 *(Go to D)*<br>No = 2 Refused = 3<br>Don't know = 4<br>*If 2, 3, or 4 STOP.*<br>*Go to next category* | | | | D<br>If YES, what is the main reason you were not able to get this service?<br><br>See Code List |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | 1 | 2 | 3 | 4 | 1 | 2 | 3 | 4 | 1 | 2 | 3 | 4 | |
| Visits with a doctor, nurse, or assistant to take care of your HIV outpatient medical care. | | | | | | | | | | | | | |
| Visit to a medical specialist based on a referral from your doctor. | | | | | | | | | | | | | |
| Visit with a doctor, nurse, or assistant to examine or treat non-HIV health conditions. | | | | | | | | | | | | | |
| Education or counseling about HIV, HIV transmission, and how to reduce the risk of HIV transmission. | | | | | | | | | | | | | |
| Treatment adherence services to provide you with education and counseling on ways to help you routinely take HIV/AIDS medications and follow through on HIV/AIDS treatments. | | | | | | | | | | | | | |
| Case management session(s) with a case manager to help you coordinate your HIV/AIDS care and help access other services and benefits. | | | | | | | | | | | | | |
| Client advocacy where a counselor assists you to work through a particular problem in obtaining a service, obtaining benefits or in a complaint against a service provider. | | | | | | | | | | | | | |

# Summary of Three Regions

Number of consumers surveyed:                      2,131

Languages used:                                  English, Spanish

Number of municipalities covered:            1,079

Number of Q&A fields in real-time:            4,169

Number of staff hours saved:                   1,910

Grants written using needs assessment data:    3

# Bergen-Passaic TGA:

## Pioneer in Web Tools for Health Planning

# Introduction

Milagros Izquierdo, Program Director, Paterson-Bergen-Passaic TGA

# A Long Partnership

- Partnered with RDE in needs assessment & client satisfaction surveying cycles since 2005.

- Impact of digital surveying vs paper-based processes immediate.

- Timeline of needs assessment collaborations.

# A Long Partnership – Immediate Impact



Client Satisfaction Observations
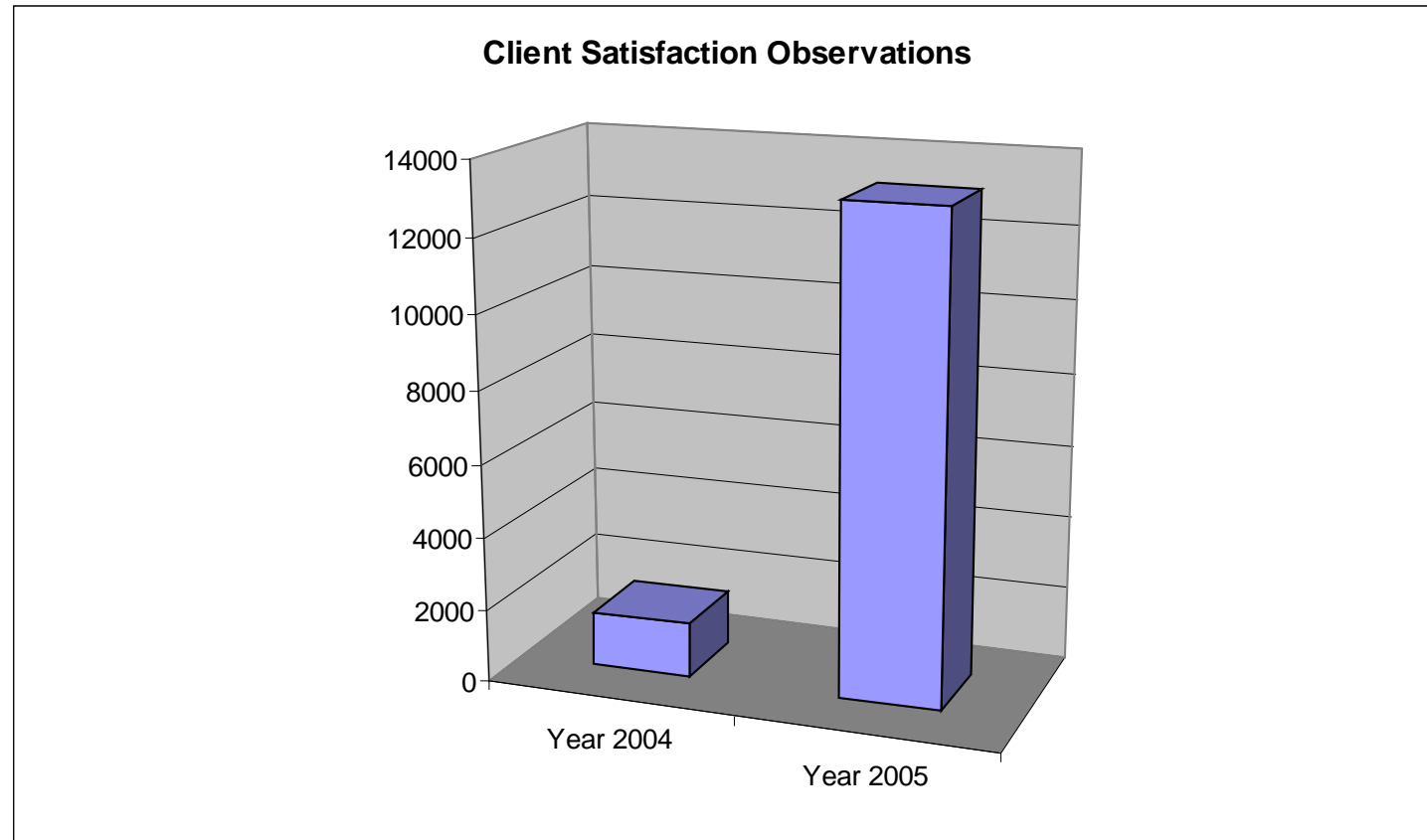
We were expecting response rates to drop in moving from paper-based to web-based surveys. Instead going web-based produced a surprising increase in response rates for a primarily urban, disadvantaged population, making internet access barriers a myth.

# Cumulative Gains

- Outcomes have drastically improved in the Bergen-Passaic TGA over time.

- Rate of incidence has decreased from 201 in 2011 to 95 in 2017.
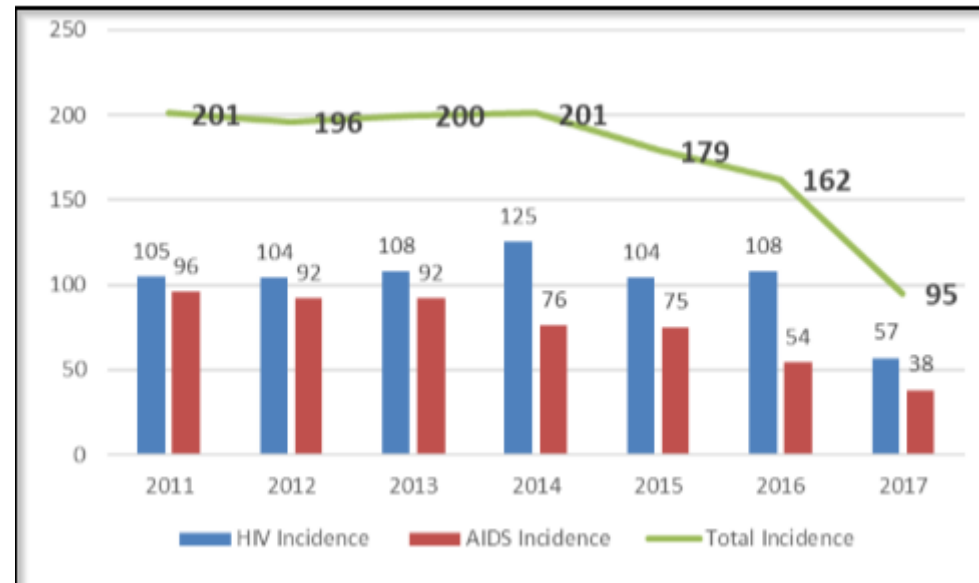
# Cumulative Gains

- Additionally, viral load suppression among the population has increased from 72% in 2016 to 91% in 2017.
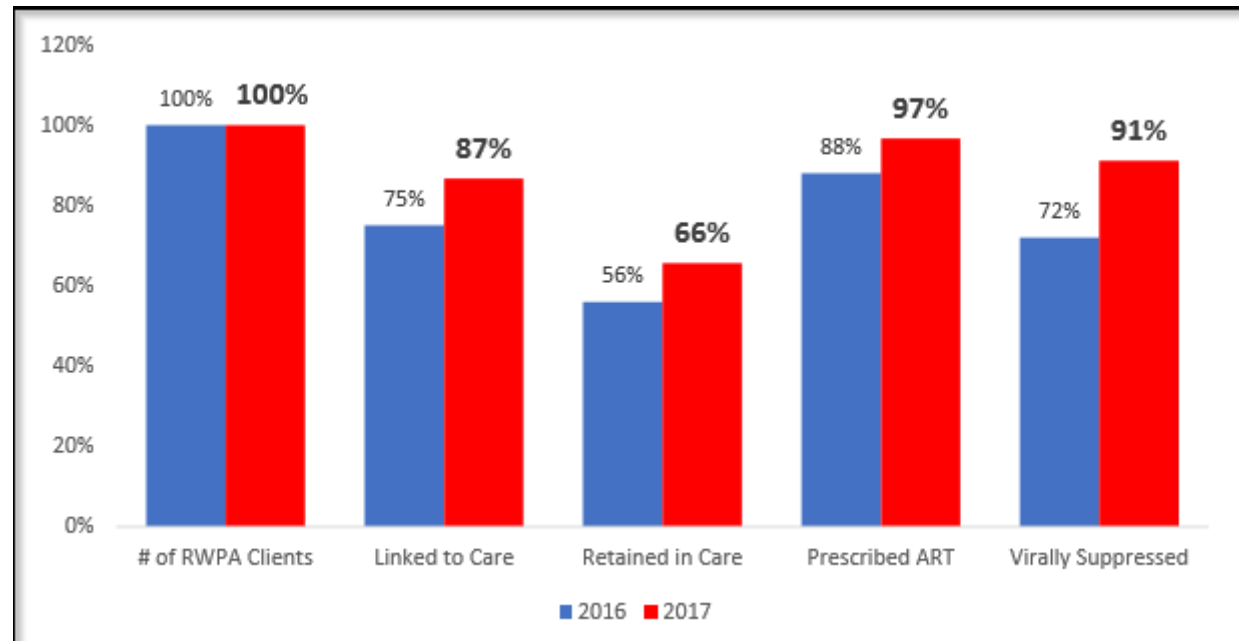
# Cumulative Gains

- Regular needs assessment cycles have been key to this success.

- Allow for opportunity to study outcomes and make adjustments to program planning to steer future outcomes.

# How we did it

# How we did it

- Make sure you client base's service needs are met.

- 10+ years of working with digital client satisfaction & needs assessment data simplifies this process.

- According to 2016 needs assessment, majority of PLWHA in the TGA are satisfied with the care and services they receive.

# How we did it



How easy is it to access services? (Aggregate)
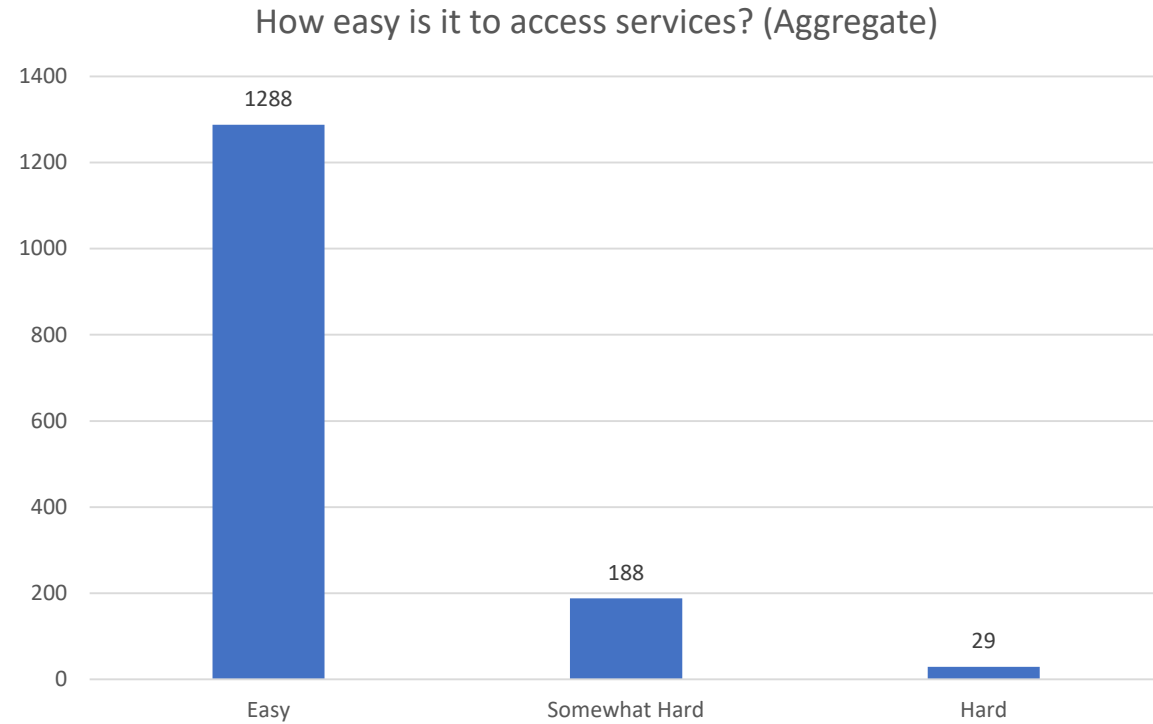
# How we did it

- Use the data to plan for the future!

- Needs assessment can be used to show current areas of need or as a tool to gain information about known unknowns.

# Future Planning

Goal: Bridge gaps of knowledge about client base.

Problem: Current data shows that majority of new clients in TGA were not diagnosed there. It is unknown where they came from.

Solution: Add place of diagnosis as a needs assessment question for the next survey wave.

# Future Planning

Goal: Identify and better serve populations of need.

Problem: The needs assessment helped identify three populations of need across the PLWHA in the TGA: African American females, heterosexual Hispanic males, and gay/bi-sexual male youth.

Solution: To be added.

# Future Planning – African-American Female Outreach

- African Americans make up 11% of the total Bergen-Passaic general population.

- 28% of all PLWH in the TGA are African-American.

- Long-standing population of need, latest needs assessment re-confirms trend.

- Strategies to address:
  - Strengthen coordination across agencies.

# Future Planning – Heterosexual Hispanic Male Outreach

- Hispanic/Latinx make up 31% of the total TGA population.

- 47% of all PLWH in the TGA are Latinx.

- Long-overlooked community with language and cultural barriers.
  - Requires special outreach needs.
  - Needs assessment highlights need across heterosexual Hispanic population, particularly among men.

- Strategies to address:
  - Enhancing communication: translation efforts.

# Future Planning – Young MSM of Color

- This community has undergone a recent increase in the TGA.

# Future Planning

- Further integration of digital needs assessment tool e2Community with eCompas EHR platform.

- Continue using and comparing data from both platforms in order to make educated health planning decisions.

- Further integration of care continuum to identify under-served populations.

# Future Planning

- Continue using an integrated, collaborative process to study needs assessment data, derive useful findings from said data, and plan for future needs assessment processes.

- Collaboration between:
  - Planning council
  - Providers
  - Consumers
  - Quality management team
  - Health policy experts

# Lessons Learned

- Use needs assessment to understand changing patterns in recipient population.

- Implement a collaborative process across providers to utilize multiple perspectives to best target your needs assessment activities.

- Decrease in incidence, increase in number of new clients.

# Des Moines, Iowa

# Introduction

Holly Hanson, Ryan White Part B Program Manager, Iowa Department of Public Health

# Previous Survey Waves

- All previous survey waves were done either in paper or with a non-specialized surveying tool, e.g. Survey Monkey.

- Paper-based surveys were mailed to clients, no need for interviewers.

- Removing paper-survey digitization step still constituted significant time savings.
    - Typically 120 hours of data entry required.
    - Process is error-prone, causing further head-aches.

# History

**2005 – Paper survey**
- Original survey developed
- Managed by program manager
- Hired consulting agency to enter raw data – took 4 weeks to receive
- Data analysis conducted in Excel by program staff

**2011 – Paper and online survey**
- Managed by temp
- Paper survey data entered into Survey Monkey (110 hours)
- Paper and online results displayed in Survey Monkey (separately)
- Other data analysis conducted in Excel by contractor
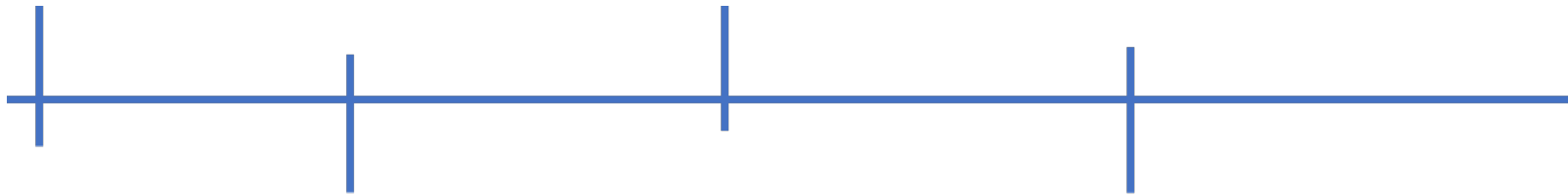
**2008 – Paper survey**
- Managed by intern/temp
- Hired consulting agency to enter raw data – took 4 weeks to receive
- Data analysis conducted in Excel by contractor

**2016 – Online survey**
- Managed by RDE Systems and temp
- Data available in real-time
- Data analyses conducted by RDE Systems
- Other data analysis conducted by program staff

# Areas of Work

1. Survey development
2. Survey pilot
3. Correspondence with contractors
4. Survey preparation and distribution
5. Data collection
6. Incentive tracking and distribution
7. Data analysis
8. Survey report

# Outreach Strategy

- Agencies with on-site outreach & resources have heavy utilization of those resources.
  - Around 50% utilization rate.
  - PCs & tablets.
  - Personal assistance.
  - Etc.

- Otherwise, respondents typically used their own equipment to access survey tool.
  - 85% utilization rate of own personal PC, tablet, or mobile phone.
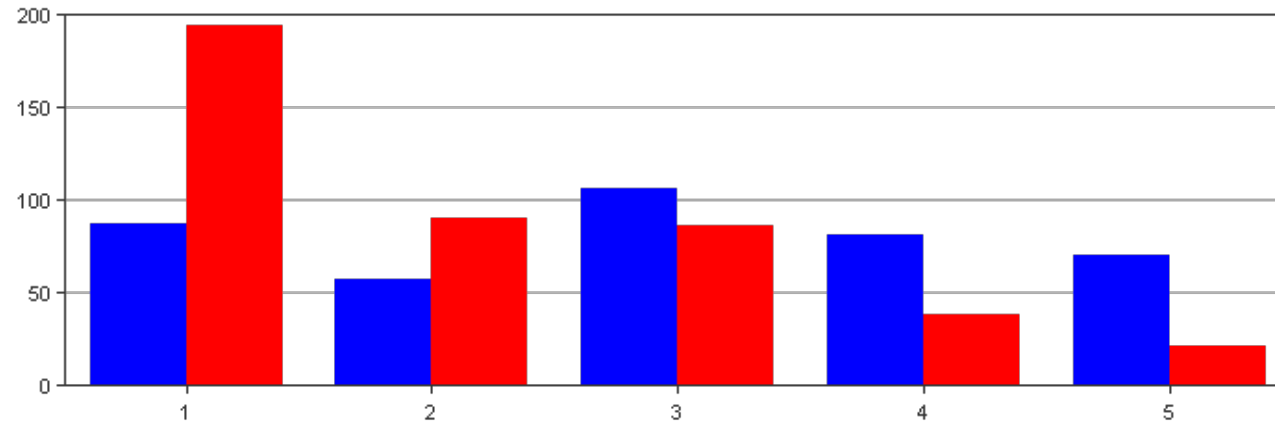
# Accessibility features include:

- Mobile & tablet compatibility!

- Multi-language capability.

- Audio playback for all texts.
  - Mobile compatible.
  - Fully translatable.

- Survey progress saving.

# Strong data-backed conclusions made mid-survey wave!

# Data Analysis: Visual Analytics

## 8902. ACE Score



| Answer | Count | Percentage |
|---|---|---|
| 1. 0 | 87 | 20.14% |
| 1. Iowa Population Estimate - 0 ACEs | ~194.4 | 45% |
| 2. 1 | 58 | 13.43% |
| 2. Iowa Population Estimate - 1 ACEs | ~90.72 | 21% |
| 3. 2-3 | 106 | 24.54% |
| 3. Iowa Population Estimate - 2-3 ACEs | ~86.4 | 20% |
| 4. 4-5 | 81 | 18.75% |
| 4. Iowa Population Estimate - 4-5 ACEs | ~38.88 | 9% |
| 5. 6-8 | 70 | 16.20% |
| 5. Iowa Population Estimate - 6-8 ACEs | ~21.6 | 5% |
| Total: | | 432 |

# Data Analysis: Mid-Survey Results



ACE Scores
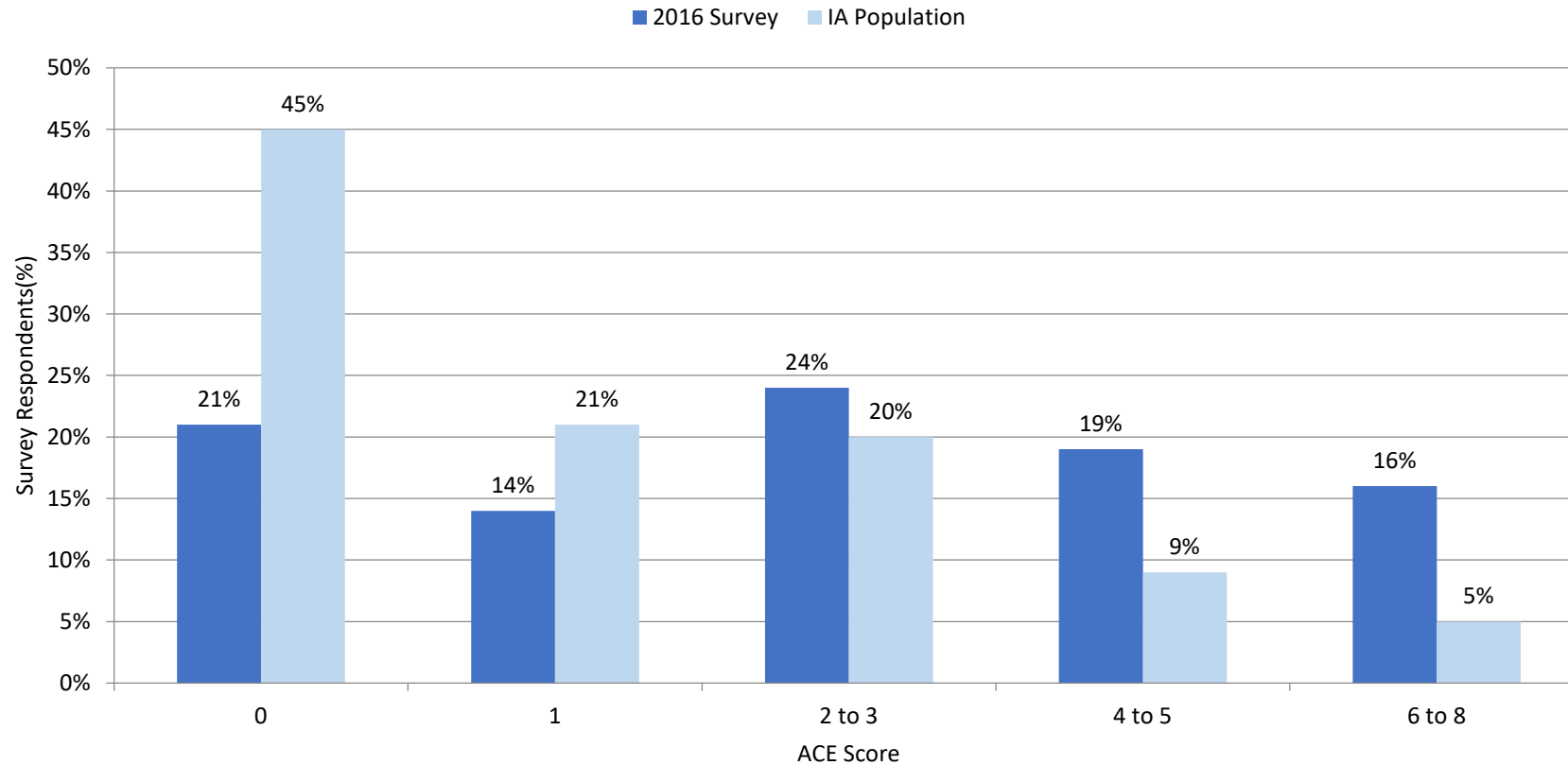
# Data Analysis: Final Results



ACE Scores

■ 2016 Survey    ■ IA Population

| ACE Score | 2016 Survey | IA Population |
|-----------|-------------|--------------|
| 0 | 20% | 45% |
| 1 | 13% | 21% |
| 2 to 3 | 25% | 20% |
| 4 to 5 | 19% | 9% |
| 6 to 8 | 16% | 5% |
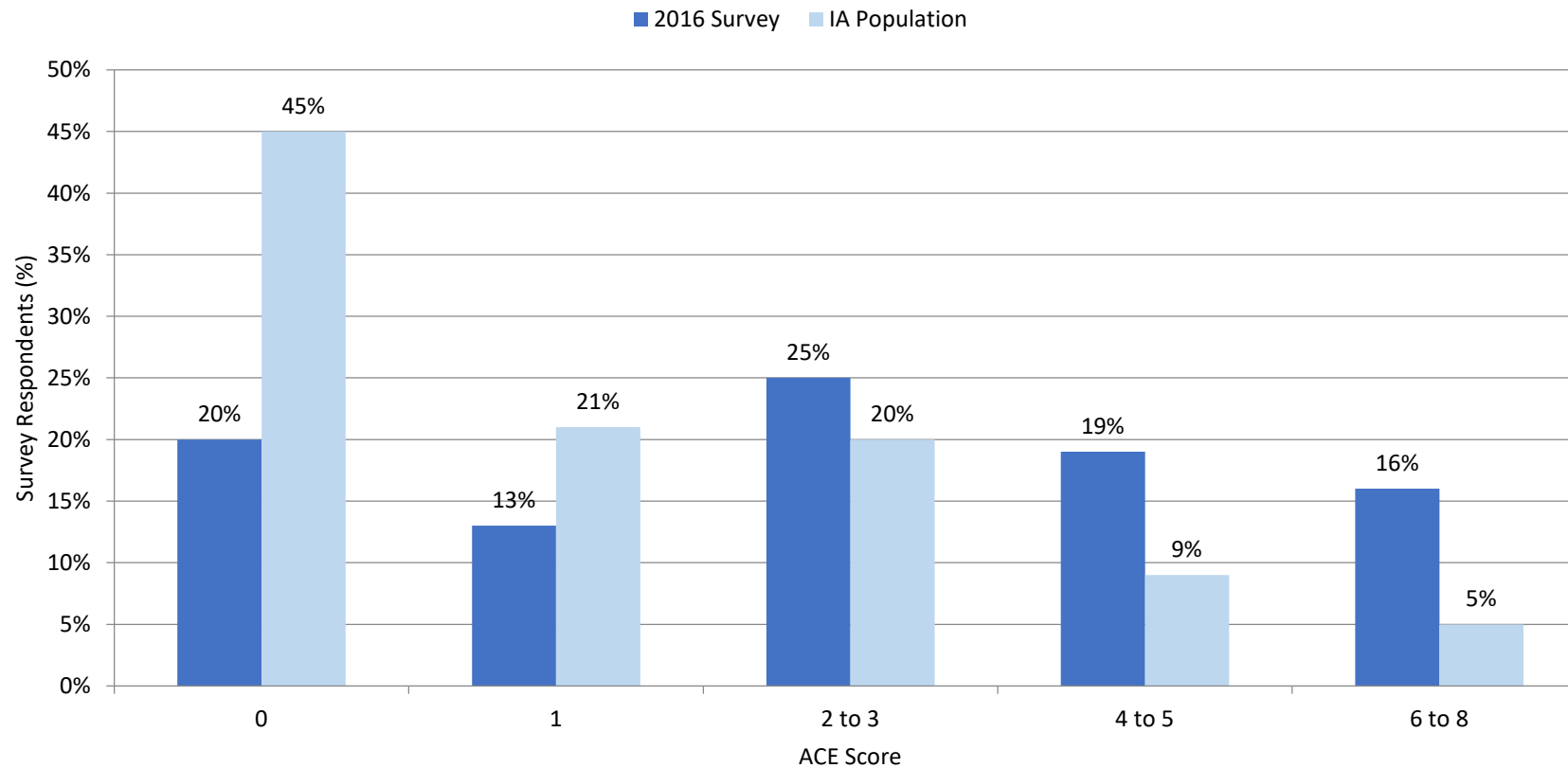
# Data Analysis: Visual Analytics

8904. Prevalence of Individual ACEs in Iowa
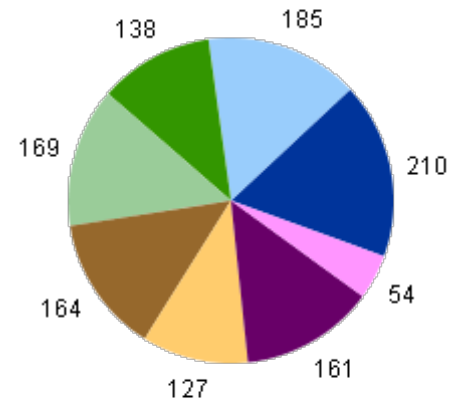


| Answer | Count | Percentage |
|---|---|---|
| 1. Emotional Abuse | 210 | 60.87% |
| 2. Physical Abuse | 185 | 53.62% |
| 3. Sexual Abuse | 138 | 40.00% |
| 4. Adult SUbstance Abuse | 169 | 48.99% |
| 5. Parental Seperation/Divorce | 164 | 47.54% |
| 6. Mental Illness among Adults | 127 | 36.81% |
| 7. Violence between Adults | 161 | 46.67% |
| 8. Incarcerated Household Member | 54 | 15.65% |
| Total: | | 345 |

# Data Analysis: Mid-Survey Results



**Prevalence of Individual ACEs**
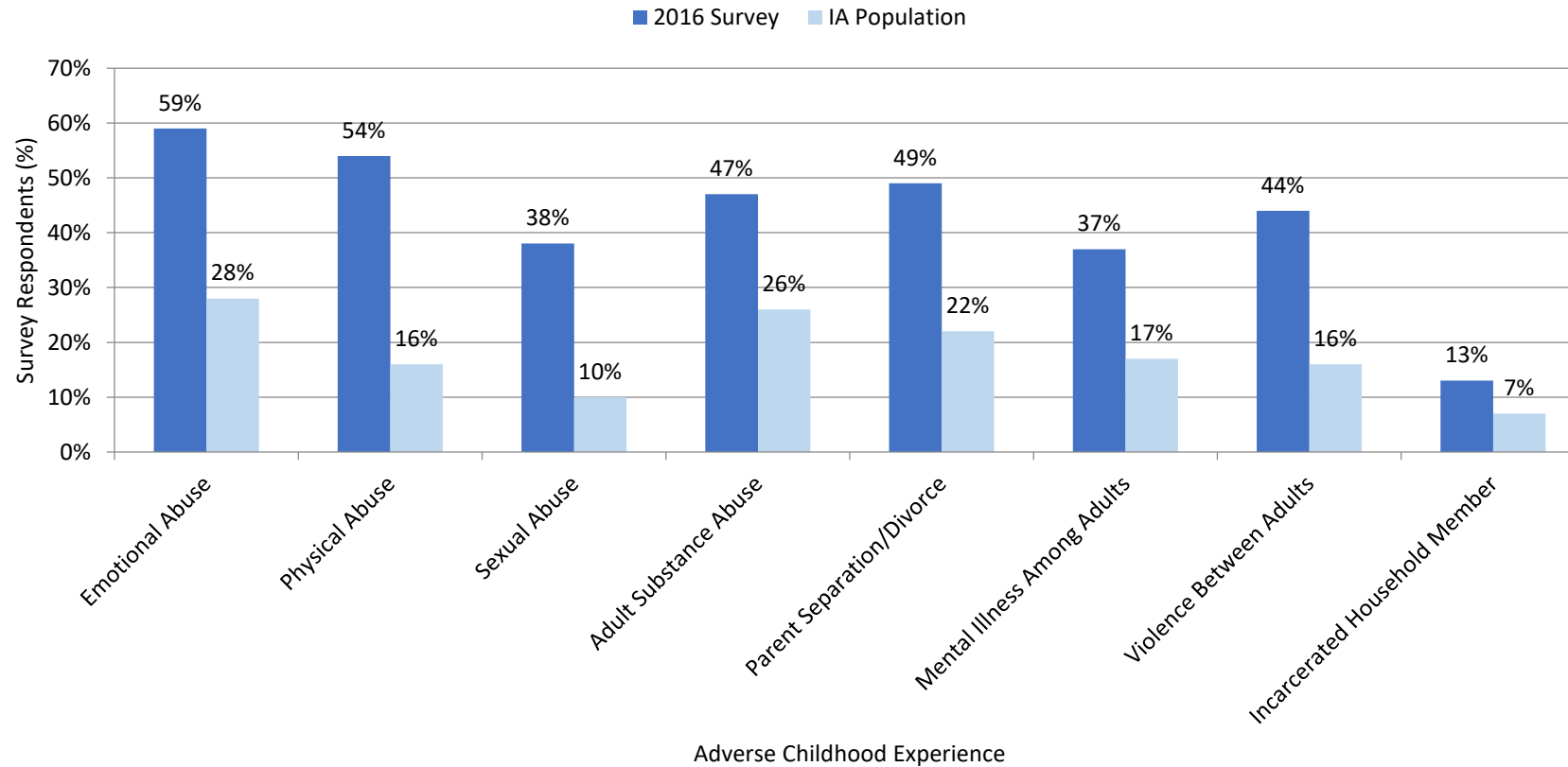
# Data Analysis: Final Results



**Prevalence of Individual ACEs**

■ 2016 Survey ■ IA Population

| Adverse Childhood Experience | 2016 Survey | IA Population |
|---|---|---|
| Emotional Abuse | 61% | 28% |
| Physical Abuse | 54% | 16% |
| Sexual Abuse | 40% | 10% |
| Adult Substance Abuse | 49% | 26% |
| Parent Separation/Divorce | 48% | 22% |
| Mental Illness Among Adults | 39% | 17% |
| Violence Between Adults | 47% | 16% |
| Incarcerated Household Member | 16% | 7% |

Survey Respondents (%)

Adverse Childhood Experience
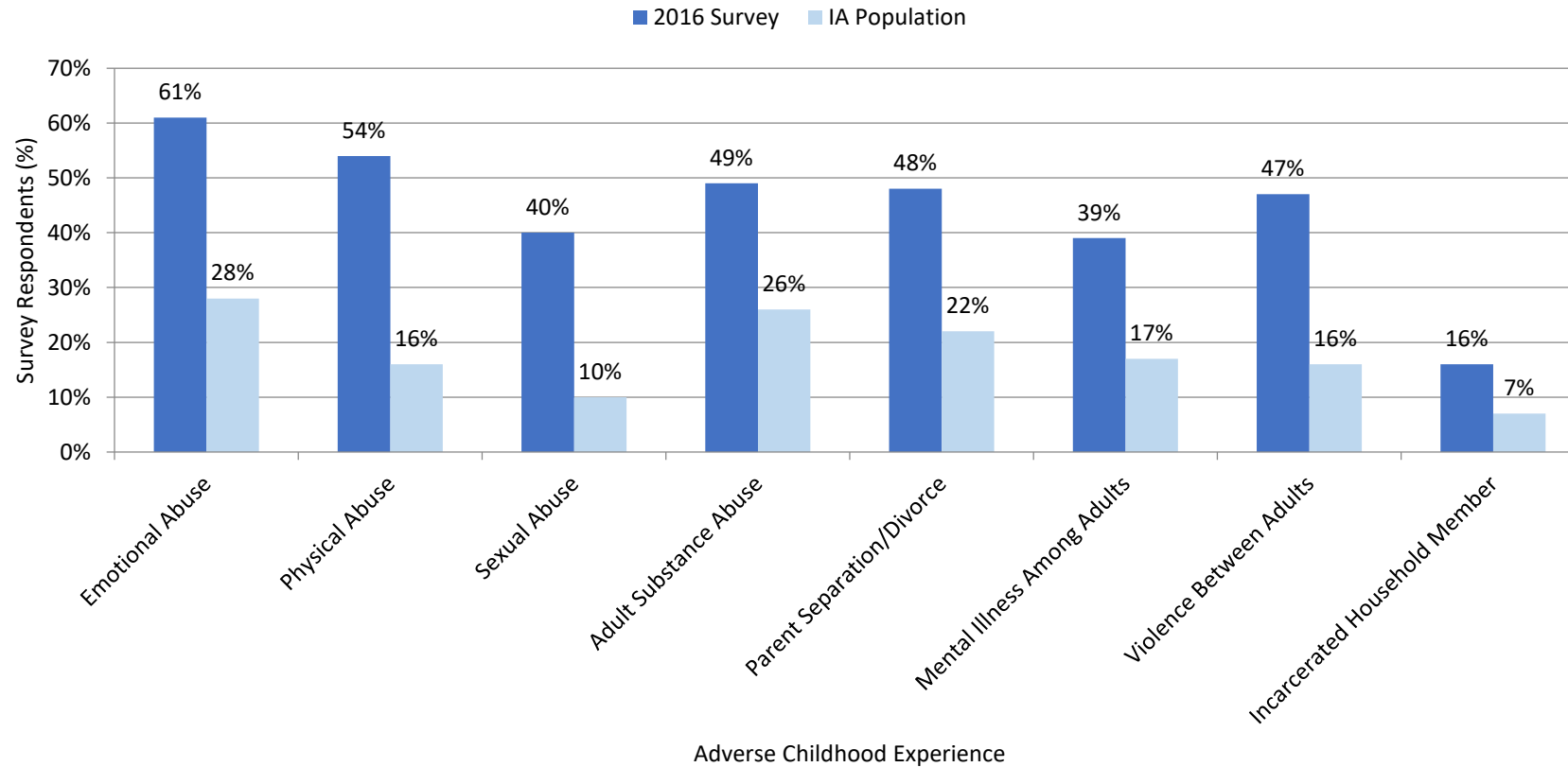
# Data Analysis: Crossing Data



15. Have you ever experienced homelessness?
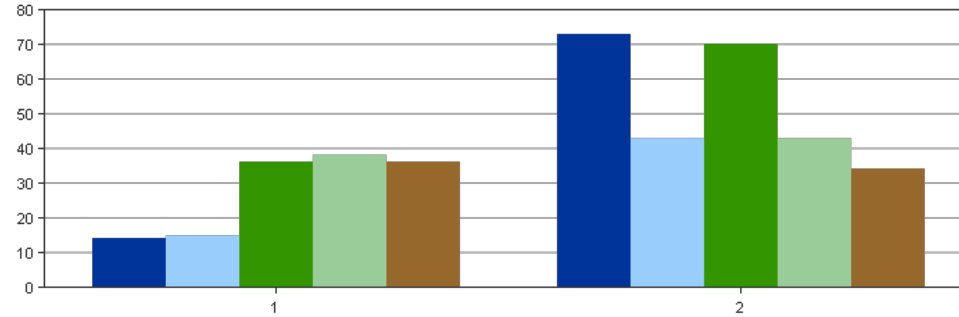
| Answer | Count | Percentage |
|--------|-------|------------|
| **0** | | |
| 1. Yes | 14 | 16.09% |
| 2. No | 73 | 83.91% |
| Total: | 87 | 100.00% |
| **1** | | |
| 1. Yes | 15 | 25.86% |
| 2. No | 43 | 74.14% |
| Total: | 58 | 100.00% |
| **2-3** | | |
| 1. Yes | 36 | 33.96% |
| 2. No | 70 | 66.04% |
| Total: | 106 | 100.00% |
| **4-5** | | |
| 1. Yes | 38 | 46.91% |
| 2. No | 43 | 53.09% |
| Total: | 81 | 100.00% |
| **6-8** | | |
| 1. Yes | 36 | 51.43% |
| 2. No | 34 | 48.57% |
| Total: | 70 | 100.00% |

# Further Data Analysis: Final Results



**% Ever experienced homelessness**

Chart showing Survey Respondents (%) by ACE Score:
- 0 ACEs: 16%
- 1 ACE: 26%
- 2-3 ACEs: 34%
- 4-5 ACEs: 47%
- 6-8 ACEs: 51%
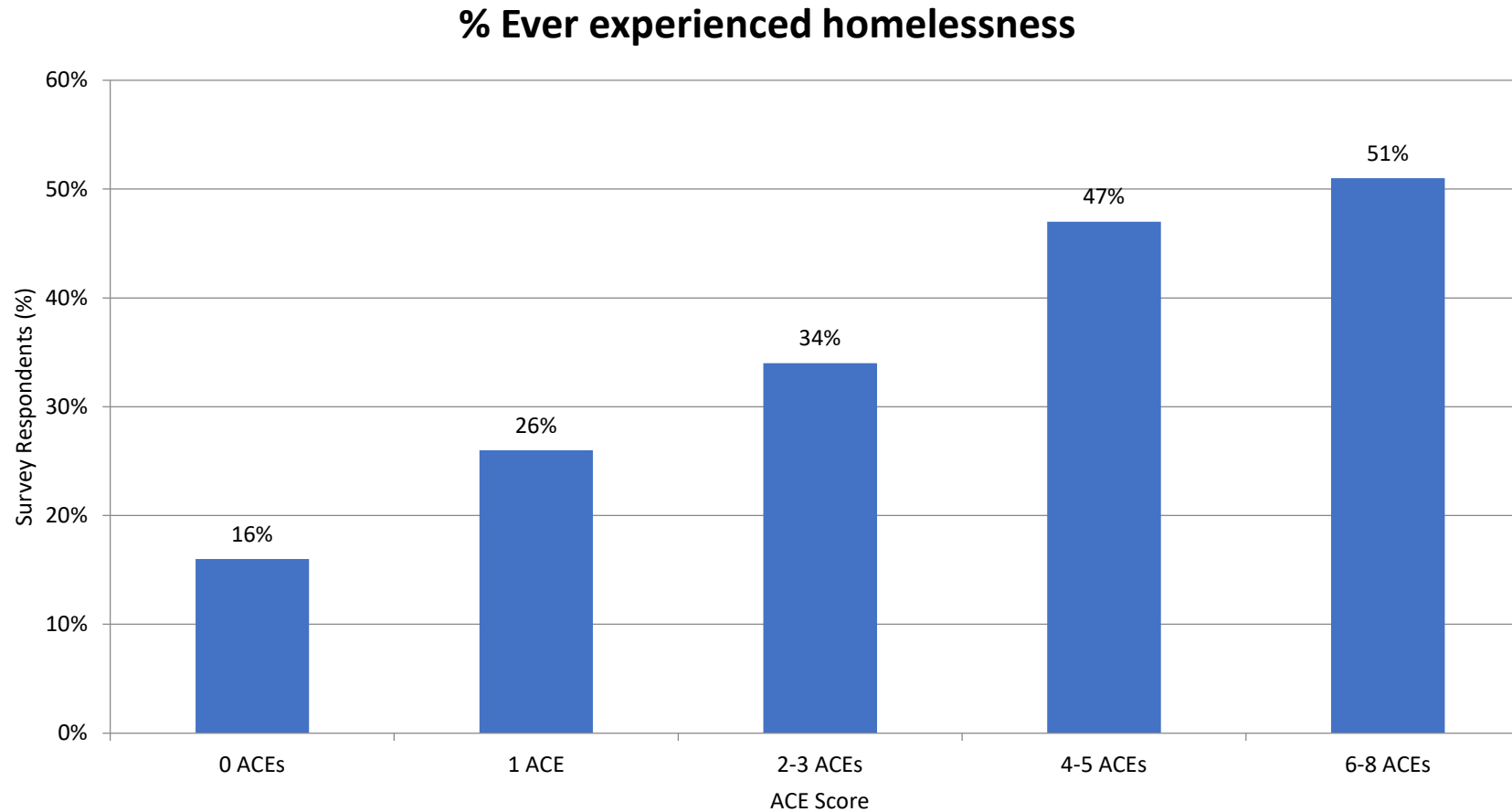
# Conclusion about Online Surveys

- Save staff time

- Do not rely on competence of staff

- Reduce burden for clients

- Allow for:
  - Real-time analysis of data
  - Greater in-depth analysis of data
  - Faster dissemination of data

# Lessons Learned

- Early in the process:
  - Consider alterations you will need to make to survey instrument for online use early
  - Design reporting instruments to dig down to the information you need.

- Factor contract procurement into timetable.

- Review real-time analytics to adjust population outreach effort.

Dallas County, Texas

# Introduction

Justin Henry, Health Planner, Ryan White Planning Council Dallas, TX

Nancy Erickson, Principal, New Solutions Inc.

# Background

- Has performed a digital needs assessment in 2013 and 2016.

- Previously maintained a paper-based process.

- Digital process key element to quick turn-around times.

# Challenges Met

- Old paper process gathered same quantity of surveys as digital process: 600 surveys total.

- However, old process would take many months, while digital would collect the same amount of data in weeks.

- 2016 digital survey wave completed in time window that would have been impossible with old paper collection method.

# Continuing Trends

- Numerous continuing trends persisted between the 2013 and 2016 survey waves:
  - Service categories with lowest satisfaction ratings persisted.
  - Same groups of greatest need persisted.

- Persistence of these trends prompted strong reaction from the planning council & community.

# Continuing Trends – Special Populations

African-American Females

Youth

Transgendered

Gay / Bi-Sexual Males

# Continuing Trends - Services

Dental

Outpatient Medical

Food Bank

ADAP

Medical Case Management

# Results from Data

- Data from the two needs assessment waves were compelling enough to prompt strong action from the planning council, even reforming it's governing documents to better address the issues that arose.

- Recognition that responding to needs exposed by the needs assessment would require additional effort prompted the creation of the Needs Assessment Committee.

- This committee was written into the bylaws of the planning council.

# Results from Data – Needs Assessment Committee

- Goal is to better prepare the council for needs assessment survey waves.

- Meets monthly and makes meeting minutes public.

- Needs assessment now a priority of the planning council.

- Research targeting special populations and avoiding tight operation windows through planning out the process well ahead of time.

# Results from Data – Needs Assessment Committee

- Targeting special populations of needs with additional outreach and needs assessment / satisfaction survey efforts.

- GOAL: Include 1% of all special population in needs assessment efforts.
  - Approximately 150-200 people per special population.

- Outreach to special populations can still be a challenge.

# Results from Data – Service Improvements

- Lack of service improvements between 2013 and 2016 was a glaring need exposed by the needs assessment that needed to be addressed by the planning council.

- Lack of access or funding for services is largest barrier for consumers.

- In response, emphasis for increasing capacity has been added.

# Lesson Learned – Organization & Communications

- Make sure all promotion and advertising material is correct.

- Make sure that question language is tailored to the expected literacy level of population and that all translations are correct.

- Furthermore, any questions written to target a specific special population should be written in language that is common and acceptable to that population.

- Make sure that survey instrument is well-tested against general population and each targeted special population.

# Lesson Learned – Cont.

- Make sure there is ample time to plan all needs assessment activities: don't try to do too much in a short timeframe!

- Needs assessment is an outreach opportunity.
  - Gives the planning council an additional window to interact with the community.

- Additionally, needs assessment helps the planning council reach out to clients who have fallen out-of-care.
  - The needs assessment is a perfect opportunity to get them back in-care!

# Q & A

# Wrap Up

# Replication and expansion

1. Client Satisfaction

2. Rolling Needs Assessment

3. Tailored Action Buttons

4. Statistical Reporting

5. Online, Interactive Resource Guide

# Feedback on e2 approach

- *"Survey Monkey is an ok tool but only has canned reporting and is not helpful for low-literacy outreach.*

  *E2Community has customizable analytics which are very helpful, and the audio playback feature saves many hours of staff time. "*

  *– Needs Assessment Consultant*

- *"Although many providers seemed to be hesitant and wary of an electronic tool at first, many of them finally opened up to the idea and saw how simple the process actually was.*

  *I also anticipate that they will be glad to get reports on client satisfaction back to them sooner than they would have with a paper survey."*

  *– Field Research Assistant*

# Feedback on e2 approach

- *"We do want to commend you guys on the ease of use of your system. This part has been so remarkably easy! Thanks for making this as painless as possible!"*

  *– RW Data Manager*

- *"We are really starting to see the advantages of having an electronic tool for this survey process."*
  *– Research & Evaluation Director*

Thank you for your time!

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