Building a Platform to Present Data:
Lessons from a Tool to Monitor Children’s Health and Well-Being

APDU
July 17, 2018

Lori Turk-Bicakci
Beth Jarosz
Samantha Sangenito
What is Kidsdata?
High-quality, wide-ranging, local data for those who work on behalf of children

Lori Turk-Bicakci, Ph.D.
| Support Lucile Packard Children's Hospital Stanford | Program for Children with Special Health Care Needs | Kidsdata.org |

**Kidsdata**

When you need data to support improvements in the health and well-being of California children, kidsdata makes it easy to find.

Visit kidsdata.org
Social Determinants of Health

- Economic Stability
- Health Care
- Environment
- Community
- Education System

Source: Adapted from Healthy People 2020
Structure
Features
Outreach
Staffing
Analytics
Find data about the health and well being of children in communities across California:

Enter a location and/or a topic, e.g. “Los Angeles foster care”
See Data by Topic

Make a selection:
(Expand all | Collapse all)

- Child and Youth Safety
  - Bullying and Harassment at School (summary)
  - Child Abuse and Neglect (summary)
  - Intimate Partner Violence (summary)

- Childhood Adversity and Resilience (summary)
  - Children with Two or More Adverse Experiences (Parent Reported) by Legislative District
  - Children Who Are Resilient (Parent Reported) by Legislative District

- Prevalence of Childhood Hardships (Maternal Retrospective)
  - by Family Income (CA Only)
  - by Maternal Age (CA Only)
  - by Prenatal Insurance Coverage (CA Only)
  - by Race/Ethnicity (CA Only)
  - Basic Needs Not Met
  - Basic Needs Not Met, by Family Income (CA Only)
  - Basic Needs Not Met, by Maternal Age (CA Only)
  - Basic Needs Not Met, by Prenatal Insurance Coverage (CA Only)
  - Basic Needs Not Met, by Race/Ethnicity (CA Only)
## Health Status

### Related Data
- Why This Topic Is Important
- How Children Are Faring
- Policy Implications

### Research & Links

### See Definition, Source & Notes

### Table

<table>
<thead>
<tr>
<th>Location: (hide)</th>
<th>Year(s): (edit)</th>
<th>Health Status: (edit)</th>
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<tbody>
<tr>
<td>45 selected</td>
<td>2013-2014</td>
<td>All</td>
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**California**

<table>
<thead>
<tr>
<th>California</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Excellent or Very Good</td>
<td>74.1%</td>
</tr>
<tr>
<td>Good</td>
<td>20.6%</td>
</tr>
<tr>
<td>Fair or Poor</td>
<td>5.3%</td>
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</table>

**Clear All**
Download & Other Tools

- **Copy** this table into:
  - Word
  - Powerpoint

- **Download** data to a formatted Excel file:
  - Data you are currently viewing
  - All data for this indicator

- **PDF**: Get a print-friendly, two-page overview of this topic for California.
  - Topic PDF
    - Include your graphic or table in the PDF

- **Embed** this table or graph on your website or blog.
  The graph will automatically update whenever data are added to kidsdata.org.
  - Pick size and get code

COPY
DOWNLOAD
BUILD PDF
PREVIEW
Learn More About Health Status

- Related Data
- Why This Topic Is Important
- How Children Are Faring
- Policy Implications
- Research & Links
Outreach

Kidsdata News

Social Media

@kidsdata

Presentations

Partnerships

- ACEs Connection
- Essentials for Childhood Initiative (CDPH)
- Campaign to Counter Childhood Adversity (4CA)
Structure
Features
Outreach
Staffing
Analytics
Website Analytics and Survey Findings

Role in which most often use kidsdata.org

- Non-profit/program staff: 39%
- County agency staff: 19%
- Health care staff: 6%
- Other: 20%
- State agency staff: 4%
- Pre-K-12 staff: 8%
- College staff: 4%
- Other: Consultant, Advocate, Federal agency staff, Attorney, Librarian, Researcher

How Often Use Kidsdata.org

- Monthly: 36%
- Several times a year: 44%
- Weekly: 11%
- Daily: 2%
- New user: 5%
- Once a year or less: 2%
- New user: 5%
Posting to social media
Writing informational material
Conducting policy work
Conducting advocacy
Planning to meet goals
Evaluating outcomes
Conducting research
My own interests
Writing grant proposals
Preparing presentations
Writing reports
How kidsdata.org is Used (pct)

Other: Expert witness testimony, stay up to date on statistical trends, teach college students, find baseline, establish benchmark figures, finds ways to better serve kids
Who is Using Kidsdata.org?
How is Kidsdata.org built?

Beth Jarosz @DataGeekB
July 2018
Children and Families

PRB analyzes and synthesizes a broad array of demographic data and research to help child advocates and decisionmakers understand key trends in child and family well-being and their implications.
Dozens of Data Sources
Hundreds of Indicators
Millions of Data Points
Consider, Curate, and Standardize

- What need are you filling?
- What data are available?
- Who is your audience and what will be most useful?
- How should data be standardized?
Before you begin...

**Learn**
- Read, review what others have done
- Ask experts
- Ask potential users

**Curate**
- Build your wish list
- Find out what’s out there
- Choose (Outcome measures? Risk measures? Both?)
- Consider value

**Standardize**
- Process and documentation
Learn What Users Need and Want

- Website
- Geography
- Timeframe
- Subgroup(s)
- Topics
Example: Environmental Health

NIH National Institute of Environmental Health Sciences
Your Environment, Your Health

Example: Environmental Health

Environmental Topics

Children's Environmental Health

National Environmental Public Health Tracking

Children's Environmental Health

Protecting

Children are often more vulnerable than adults because they are growing and their bodies are still forming. They may be at greater risk if they are exposed to environmental contaminants. Contaminants are anything that can cause something to become unclean, polluted, or not pure. They can be found anywhere and are unsafe. A toddler playing in dirt contaminated with high levels of lead can become sick from lead poisoning. A child with asthma playing outside when the air quality is bad may have an asthma attack.

Environmental hazards are not just outside. They can also be found inside a child's home or school. Children living in older homes with lead-based paint can get sick from breathing lead dust or swallowing chipping paint.
Huge body of research links elevated blood lead levels in childhood to a wide variety of physical and mental health problems.
Choose and Collect Lead-Related Indicator(s)

Lead exposure risk
- Age of housing
- Lead levels in drinking water
- Proximity to point-source pollution

Blood lead levels

Health outcomes
- Developmental delay
- Learning difficulty
Be Curious

What do these data really measure?

What’s the universe: Are these data for all children? All people? Those who participate?

Are the data ever revised?

What suppression rules have (already) been applied to the data?

Are the data from a survey, administrative records, or some other source?

Has the methodology changed over time?
Example: E.H. → Lead Exposure → Blood Lead Levels

What we learned:
• Data are for “counties,” but Berkeley isn’t a county!
• Data are only for those children who are tested
• Thresholds for measurement changed over time
Every Data Source is Different

Unpublished Microdata
- Birth records
- Death records

Published Microdata
- School staffing
- Survey microdata

Custom Tabulations
- Hospital discharges
- Asthma
- Homelessness

Published Tables
- Academic outcomes
- Juvenile arrests
- Blood lead levels
- Immunization rates
- Demographics

Develop Custom Estimates
- Local area child health
- Demographics*
Standardize

Children/Youth with Elevated Blood Lead Levels, by Age
(change indicator)

Be consistent…

- **Geographic coverage** (counties, cities, districts)
- **Temporal coverage** (annual, monthly)
- **Data types** (numeric, percent, rate)
- **Documentation**

<table>
<thead>
<tr>
<th>Location: (hide)</th>
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<td>California</td>
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<td>Percent</td>
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<td></td>
<td>Ages 0-5</td>
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<td></td>
<td></td>
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<tr>
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<td>Ages 6-20</td>
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<td></td>
<td></td>
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<tr>
<td></td>
<td>Total for Ages 0-20</td>
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<table>
<thead>
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<tr>
<td>Ages 0-5</td>
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</tr>
<tr>
<td>Ages 6-20</td>
<td>0.5%</td>
</tr>
</tbody>
</table>
Process

1. Review the data
2. Clean & Reformat
3. Document
4. Quality Control
5. Publish

The process is cyclic, with feedback loops indicating continuous improvement and review.
Develop a Quality Control Checklist and an Error Log

- Check for common errors (checklists help!)
- Keep “Error Log” of mistakes
- Use patterns in Error Log to refine your QC checklist

- If something looks wrong, RE-READ EVERYTHING & be willing to ask (more) dumb questions

The Trick To Surviving A High-Stakes, High-Pressure Job? Try A Checklist

October 30, 2017 · 9:00 PM ET

Hidden Brain episode “Check Yourself”
https://www.npr.org/2017/10/30/559996276/the-trick-to-surviving-a-high-stakes-high-pressure-job-try-a-checklist
Write Good Metadata: What do Users Need to Know?

- Go back to your “curiosity” questions
- Minimum
  - Definition
  - Universe
  - Original data source (include URL if appropriate)
  - Date
  - Reliability and/or suppression
  - Changes over time (e.g., survey methods changed in 20YY, compare with caution)
  - Caveats, cautions, or warnings (e.g., parts may not sum to 100% due to overlap between categories)
- Also nice
  - Example of how to interpret the numbers
  - Historical trend and/or policy context
Example: Blood Lead Levels

Definition: Number of children/youth ages 0-20 with blood lead levels at or above 9.5 micrograms per deciliter, among those screened, by age group (e.g., among California children ages 0-5 screened in 2013, 1,288 had an elevated blood lead level).


Footnote: Medicaid and state regulations require that every child in a government-funded health program be screened for blood lead level at 12 months and again at age 2. When a blood test is missed, health care providers are required to screen the child at the first opportunity up to age 6. It is also recommended that health professionals screen any child or youth who exhibits symptoms of lead exposure, has known lead exposure, or is considered to be at risk for lead exposure. For children/youth who receive multiple tests, it is their highest blood lead level, and their county of residence at the time of their highest blood lead level, that is reported. Data exclude results determined to be false positives or clerical errors. The abbreviation S refers to data that have been suppressed because there were fewer than 20 children/youth screened for blood lead level.
Indicate Reliability

Options

- Publish margins of error
- Flag values that are more (or less) reliable
- Set thresholds for display, and only show those that meet your reliability threshold

“The abbreviation S refers to data that have been suppressed because there were fewer than 20 children/youth screened for blood lead level.”
Repeat: Document Everything!

Write that letter to your future self, because your future self will wish you did.
Enjoy!
See Data by Topic

Make a selection:
(Expand all | Collapse all)

- Child and Youth Safety
- Children with Special Health Care Needs
- Demographics
- Education & Child Care
- Emotional & Behavioral Health
- Environmental Health
  - Air Quality (summary)
  - Lead Poisoning (summary)
  - Water Quality (summary)
The ACE Pyramid - Mechanisms by which Adverse Childhood Experiences Influence Health and Well-Being Throughout the Lifespan

Felitti, V. & Anda, RF The Relationship of Adverse Childhood Experiences to Adult Health Status
A Collaborative effort of Kaiser Permanente and The Center for Disease Control
http://www.cdc.gov/ace/

Slide Courtesy of Rob Anda, MD, MS
Impact of Toxic Stress on the Brain and Body

**Impact of Toxic Stress on the Brain and Body**

**Adverse Childhood Experiences**
- Abuse and Neglect (e.g., psychological, physical, sexual)
- Household Dysfunction (e.g., domestic violence, substance abuse, mental illness)

**Impact on Child Development**
- Neurobiologic Effects (e.g., brain abnormalities, stress hormone dysregulation)
- Psychosocial Effects (e.g., poor attachment, poor socialization, poor self-efficacy)
- Health Risk Behaviors (e.g., smoking, obesity, substance abuse, promiscuity)

**Long-Term Consequences**

**Disease and Disability**
- Major Depression, Suicide, PTSD
- Drug and Alcohol Abuse
- Heart Disease
- Cancer
- Chronic Lung Disease
- Sexually Transmitted Diseases
- Intergenerational transmission of abuse

**Social Problems**
- Homelessness
- Prostitution
- Criminal Behavior
- Unemployment
- Parenting problems
- High utilization of health and social services
- Shortened Lifespan

**Crucial Parts of the Brain Affected by Toxic Stress**

- **Hypothalamus**: Links the nervous system and the endocrine system
- **Prefrontal Cortex**: The part of the brain that processes information to make informed decisions; higher-level executive functioning, planning, decision-making center
- **Amygdala**: The part of the brain that processes emotions
- **Hippocampus**: The part of the brain that stores memories
Supporting Communities to Accelerate ACEs Science
These teens saw how poor mental health hurt their peers. So they got a law passed. [washingtonpost.com]

LUKE JOHNSON 7 HOURS AGO

These teens saw how poor mental health hurt their peers. So they got a law passed.

ACEs Science resources, webinars, how-tos

ACES SCIENCE 101

GOT YOUR ACE, RESILIENCE SCORES?

Do the ACEs & resilience questionnaires.
Learn about other ACEs.
California ACEs Action
A group of practitioners, healers, policy advocates and all other people committed to making California a place that is healthy and safe for everyone.

Recent Blog Posts

**Policymaker Education Day Registration STILL OPEN!**

GAI LIN - 5/4/18 3:19 PM

Registration is still OPEN for another week to the second annual Policymaker Education Day hosted by the California Campaign to Counter Childhood Adversity (4CA) in Sacramento on May 22nd! Don't miss this opportunity to be able to share your thoughts and expertise with your Assemblymember or Senator on how to address childhood adversity in your communities. Guest speakers include Assemblymember Dr. Arambula of Fresno County, Ted Lempart of Children Now and Sarah Pauter of Phenomenal...

READ STORY 0 COMMENTS
Preparations begin for 2018 State Legislative Sessions—Tools to help you communicate with your state legislators

California ACEs Action
A group of practitioners, experts, policy advocates and other people committed to making California a place that is healing and safe for everyone.

California’s Child Poverty Rate Highest in Country
Kasita and Public Policy Institute of California (PPIC) have partnered to calculate the state’s child poverty rate, which has been rising since the recession in 2008. This year, California’s child poverty rate reached an all-time high of 24.4 percent.

California ACEs Action
A group of practitioners, experts, policy advocates and other people committed to making California a place that is healing and safe for everyone.

Save the date! National ACEs Conference, Oct. 15-17, San Francisco, CA

2018 ACEs Conference & Pediatric Symposium
OCTOBER 15 - 17

The Center for Youth Wellness and ACEs Connection are hosting the third annual ACEs Conference Oct. 15-17, 2018, at the Hyatt Embarcadero in San Francisco. This year’s event will feature a pediatric symposium and a keynote address by Dr. Nadine Burke Harris.
Growing Resilient Communities 2.0

EDUCATE
- Speakers Bureau
- Content
- Presentations
- Feedback

ENGAGE
- Join The Movement
- ACEs Science
- Local Government

CELEBRATE
- Tell your ACEs Initiative's Story
- Host Events

ACTIVATE
- Develop Policy
- Organize ACEs

Growing Resilient Communities 2.0

ACEs Connection Network
acesconnection.com
acesarehigh.com
California Essentials for Childhood Common Agenda

- **Vision:** All California children, youth and their families thrive in **Safe, Stable, Nurturing Relationships and Environments**

- **Mission/Purpose:** To develop a *common agenda* across multiple agencies and stakeholders to **align activities, programs, policies and funding** so that all California children, youth and families have safe, stable, nurturing relationships and environments

- **Strategic Direction:** Strengthen families and communities capacities to create safe, stable, nurturing relationships and environments for children
Broader Context of Prevention

- Public health focus on primary prevention
- Life course perspective - temporal and social perspective on health and well being:
  - Developmental
    - Across life experiences (i.e., gestation, early childhood, adolescence, young adulthood, midlife, senior)
  - Across generations
  - Socio-ecological
    - Experiences are shaped by the wider social, economic and cultural context.
Shared Data and Outcomes Workgroup

- Childhood Adversity and Resilience topic link on kidsdata.org:

- California & County dashboards – www.kidsdata.org

- ACEs training with Essentials for Childhood, Berkeley Media Studies Group, ACEs Connection, First 5, Kidsdata:

- ACES Connection: https://acesconnection.shinyapps.io/sacramento_app/
Partnership with Kidsdata.org

• Working with Kidsdata.org to add three sources of Adverse Childhood Experiences (ACEs) data to their website, creating a new data topic:
  – Behavioral Risk Factor Surveillance System (BRFSS)
  – Maternal and Infant Health Assessment (MIHA)
  – National Survey of Children’s Health (NSCH)
  Child and Adolescent Health Measurement Initiative (CAHMI)
Indicators by Life Course

**Child Life Course**
- Children in poverty
- Child abuse and neglect reports
- CalFresh participation
- Households with a high housing cost burden
- Children/youth without health insurance coverage
- *Domestic violence calls for assistance (maybe)*

**Pregnancy and Birth**
- Teen births
- Preterm births
- Breastfeeding of newborns
- Infant mortality rate

**Early/Middle Childhood**
- Availability of child care for potential demand
- Children ages 3-5 not enrolled in preschool or kindergarten
- Annual cost of child care
- Young children whose parents read books with them
- Students proficient in third grade reading

**Adolescents**
- Students completing high school
- Total community assets (student reported)
- Students reporting depression-related feelings
- Bullying/harassment in the past year
San Bernardino County Data Dashboard: Child Adversity and Well-Being

A product of the CA Essentials for Childhood Initiative, the California Data Dashboard contains 23 select indicators of child adversity, health and well-being, utilizing data available on kidsdata.org. For more information about this project please go here.

- Child Life Course
- Pregnancy and Birth
- Early/Middle Childhood
- Adolescents

Children with Two or More Adverse Experiences (Parent Reported)
Year(s): 2016

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<th>0%</th>
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<th>10%</th>
<th>15%</th>
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<tbody>
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<td>18.4%</td>
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<td>San Bernardino County</td>
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<td></td>
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<td>17.0%</td>
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</table>

Have Questions?
Do you have questions? Need Help? Too many emails?

Please contact our community manager: Dr. Ariane Marie Mitchell.

Blog Directory
- ACEs Connection Info
- ACEs Task Force
- ACEs Task Force Meeting Notes
- Action Group - Awareness and Learning Collaborative
- Action Group - Research
- Action Group - Resources

Comments

Blog Archive

May 2018 (0) May 2017 (2)
Successes of the Kidsdata Widgets

- Berkley Media Studies workshops in Butte County, Alameda, Fresno, Riverside, and San Bernardino
- 4CA Policymaker Awareness day-community profiles
- Strategies 2.0 learning collaborative presents the data from all counties in their meetings. Action plans developed based on the data
- Northern CA counties assessing their ability to collect data
Recent Blog Posts

Families with Teens - Let’s Talk!

BONNIE BERMAN - 4 HOURS AGO

Want to build trust, reduce arguments, increase connection and create a new understanding with your teen(s)? Join Danielle Bisce, LCSW and Carla Lank Sibiane, MFT Associates for a Family Workshop on Tuesday, May 22nd (parents only), & Saturday, May 26th (parents & teens). Designed for parents and their 13-19 year old teenagers. This workshop will help you to: * Strengthen your bond with your teen(s) * Understand the negative cycles you get into * Learn new ways to communicate and work...

Yolo County ACN Community Tracker

Yolo County ACN Community Tracker

Yolo County ACN Community Tracker is a bird’s eye view of ACEs science data collection and display. The community tracker also shows which 11 milestones organizations have completed in their journey to incorporate trauma-informed and resilience-building practices based on ACEs science.

Given an ACEs Science Presentation?
COMPLETED SURVEY

Is your organization becoming trauma-informed?
COMPLETED SURVEY

Yolo County Data Dashboard: Child Adversity and Well-Being

You can make a difference by participating in policy maker education day! California lawmakers need to hear from you about how childhood adversity affects you and what they can do to do to prevent it.
Welcome to your Sonoma County ACEs Connection Community Tracker!

What is this?
This app helps you keep track of the ACEs science presentations your ACEs initiative has made in your community by location, sector, subsector, date and who did the presentation. It also keeps track of how the organizations in your community are moving toward implementing trauma-informed and resilience-practices based on ACEs science.

What's included in this app?
1. ACEs Science Presentations
   Presentations Map: Get a bird's eye view of all presentations, and info about each presentation. Organize the presentations by sector
   Presentation Data: Search the data by sector, subsector, presenter and organization.

2. Trauma-informed Organizations Tracker
   Tracker Map: Get a bird's eye view of all ACEs initiative member organizations participating in the journey to becoming trauma-informed and resilience-building, and where they are in that journey.
   Tracker Data: Track organizations' progress by sector and subsector, and by individual milestone. After examining a plethora of trauma-informed assessment tools for several
### Organizations that Have Received an ACEs Science Presentation

Select the Sector to Display

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<tr>
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</table>

### Examine the Presentation Data

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<tr>
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<th>Presenter</th>
<th>Attendance</th>
<th>Date</th>
<th>Sector</th>
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<tr>
<td>Equity of the Care Conference (education, community, and non-profit)</td>
<td>Jessica Pregabale</td>
<td>40</td>
<td>11/3/2016</td>
<td>Education</td>
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<tr>
<td>Grant Round for Physicians and Providers HAP</td>
<td>Dr. Catherine Confram</td>
<td>75</td>
<td>12/13/2016</td>
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<td>Marin Child Early Intervention Teams, Marin County HHS</td>
<td>Jessica Rockwell</td>
<td>12/16/2016</td>
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<td>Maternal Child Adolescent Health Advisory Board</td>
<td>Grace Harris</td>
<td>12/19/2017</td>
<td>Community Service Organization</td>
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<tr>
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<td>Nikki Jackson</td>
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<td>Jewish Family and Children’s Services PJC</td>
<td>Michelle Rogers and Ellen Bauer</td>
<td>1/10/2017</td>
<td>Social Services</td>
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<tr>
<td>23 Children’s Center staff made up of Infant, Toddler and Preschool age teachers</td>
<td>Elise Klein and Candela Pietraski</td>
<td>1/12/2017</td>
<td>Child Care</td>
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<td>DHS Field Nursing Staff</td>
<td>Liz George</td>
<td>1/18/2017</td>
<td>Health</td>
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<td>First 3 Commission</td>
<td>Michelle Rogers and Grace Harris and Jenny Shuster</td>
<td>2/20/2017</td>
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<td>0 CPR parents educators</td>
<td>Allison Berk</td>
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<td>Social Services</td>
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seeing 1 to 10 of 74 entries
Successes of the Community Trackers

• 25+ trackers and counting, with over half using the trackers for reporting to funders

• Connecting organizations across the country – Midwestern police force is in conversation with TN law enforcement

• Allowing local organizations to share ideas

• *Outcome data coming soon!*
THANK YOU!