Using Community Data to Inform a Coordinated Response for Adults with Intellectual/Developmental Disabilities

Catherine Kothari, PhD
269-501-4149  catherine.kothari@med.wmich.edu

Kathy Lentz

Objectives:

Identify potential data sources for identifying jail, emergency department and hospitalization use by persons with ID/DD

Using this data to develop a coordinated community response to meet the needs of persons with ID/DD

Notes:
Using Community Data to Inform a Coordinated Response for Adults with Intellectual and Developmental Disabilities

Why is data important?

- Magnitude & scope of problem
- Directing policy development
- Inform evidence-based practice

Workshop Objectives

- Identify potential data sources for criminal justice involvement, emergency department and hospitalization use rates for persons with intellectual/developmental disabilities

- Develop evidence-based strategies to promote a coordinated community response in meeting the needs of persons with intellectual/developmental disabilities that results in...
  - Prevention / reduction in crime victimization, crime perpetration and jail
  - Reduction in physical and mental health crises, and associated emergency department visits, medical hospitalizations and psychiatric hospitalizations
Data Collection

Practical Prep Steps

1. Identify problem / population / program of interest
2. a. List the behaviors / outcomes you are looking to change
   b. List possible indicators for each
3. Consider which indicators are most easily available
4. Partner with evaluator, QI, IT, researcher

Our Example

Data Collection
Our Example

Results

Demographics

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Race</td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Black</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hispanic</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
</tr>
<tr>
<td>High School</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Attending High School</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Employed</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unemployed</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not married</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

- NOTE: Percentages above are based upon Iowa clients.

I/DD have Lowest Level of Crime Involvement

Crime Involvement, 2000-2010

<table>
<thead>
<tr>
<th>Group</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>I/DD (631)</td>
<td>13.2%</td>
</tr>
<tr>
<td>SA (2,913)</td>
<td>19.1%</td>
</tr>
<tr>
<td>M/M (2,157)</td>
<td>34.0%</td>
</tr>
<tr>
<td>M/M/S/A (205)</td>
<td>59.5%</td>
</tr>
</tbody>
</table>
Crime Victimization Cuts Across All I/DD Groups

Predicting crime victimization among I/DD population

- None of the demographic factors predict crime victimization (age, gender, race, marital, educational level, employment status)
- Nor does having a co-occurring mental health diagnoses predict crime victimization

Co-occurring MH Strong Predictor of Crime Perpetration

Predicting crime perpetration among I/DD population

- Those with a co-occurring mental health diagnoses have nearly 7X greater odds of perpetrating a crime than those without
- This does not vary by demographics

ANY Crime Involvement by I/DD Group Associated with Double the ED Visits

Emergency Department Visit(s), 2009

<table>
<thead>
<tr>
<th>Group</th>
<th>ANY Crime Involvement %</th>
</tr>
</thead>
<tbody>
<tr>
<td>I/DD (631)</td>
<td>45.4%</td>
</tr>
<tr>
<td>SA (2,913)</td>
<td>27.1%</td>
</tr>
<tr>
<td>MH (2,357)</td>
<td>58.2%</td>
</tr>
<tr>
<td>MH/DA (200)</td>
<td>76.1%</td>
</tr>
</tbody>
</table>
Criminal Behavior Associated with Psychiatric Hospitalizations Among ID/DD Group

Psychiatric Hospitalization(s), 2009

<table>
<thead>
<tr>
<th>ID/DD (632)</th>
<th>3.3%</th>
</tr>
</thead>
<tbody>
<tr>
<td>SA (2,913)</td>
<td>7.0%</td>
</tr>
<tr>
<td>MH (2,157)</td>
<td>14.4%</td>
</tr>
<tr>
<td>MH/SA (305)</td>
<td>27.7%</td>
</tr>
</tbody>
</table>

Acute Healthcare Visits/Events

- The link between criminal behavior and ED visits has been found elsewhere, as well
- As has the connection to psychiatric hospitalizations
- The fact that criminal victimization has the same effect on ED visits, though, is new information
- Other contributors of ED utilization include:
  - severity of disability (especially feeding status & polypharmacy)
  - living in family versus group home,
  - not having a medical home
  - not having a crisis plan

Neither Crime Involvement nor MH Cooccurr. Associated with Medical Hospitalizations

Medical Hospitalization(s), 2009

<table>
<thead>
<tr>
<th>ID/DD (431)</th>
<th>11.8%</th>
</tr>
</thead>
<tbody>
<tr>
<td>SA (2,913)</td>
<td>7.1%</td>
</tr>
<tr>
<td>MH (2,157)</td>
<td>16.0%</td>
</tr>
<tr>
<td>MH/SA (305)</td>
<td>28.8%</td>
</tr>
</tbody>
</table>
CONCLUSIONS: Crime Involvement

1. Crime involvement by ID/DD consumers is relatively infrequent
   - Only 13.2% over a decade

2. When it occurs, it is more likely to be crime victimization than crime perpetration
   - Victimization cuts across ID/DD demographic groups

3. The exception is for ID/DD consumers with a co-occurring mental health diagnosis, who are more likely to commit crime than to be victims of it
   - Having a co-occurring mental health diagnosis is associated with a seven-fold increase in criminal behavior

CONCLUSIONS: Acute Healthcare Visits/Events

1. Regardless whether criminal involvement is as a victim or as a perpetrator, it is associated with more than double the emergency department visits

2. Medical hospitalizations by ID/DD consumers are not associated with criminal involvement

3. Crime perpetration is associated with psychiatric hospitalizations

4. Having a co-occurring mental health disorder is not associated with medical utilization
What We Know/Assume

- By far, most individuals with I/DD who are perpetrators also have a mental illness (7x more)
- Most individuals have history of trauma
- Most individuals have neuro-developmental disorder (FASD, early childhood trauma)
- Most individuals present with more skills than they can perform on a consistent basis
- Most individuals want a better life for themselves, they need help to get there

Daily Life Impact

- Limited coping mechanisms, unable to manage life's frustrations, emotions
- Lack of problem solving skills—what to do when something unexpected happens or things don’t go as planned
- Difficulty asking for help
- Frustration, fear, sadness expressed through aggression (verbal or physical)

Underlying Principles for Services/Supports

- Culture of Gentleness:
  - Safe
  - Respected/Valued,
  - Respecting/Valuing
  - Engaged
  - Managing Transitions/changes
  - Reducing demands
- Trauma Informed Care
  - Respecting individual's experiences, providing hope, connecting behaviors/symptoms to trauma
  
  These approaches help staff as much as individuals served...
Services/Supports to Reduce both Perpetration and Victimization

- Trauma screening (adapted Adult version of Juvenile Victimization Scale, Child PTSD Scale, Life Events Checklist)
- Biographical Timeline (Beth Barol)
- Cognitive Behavioral Therapy/Dialectical Behavioral Therapy-modified
- Medication Management/Monitoring (patterns of multiple medications)

Modifying Services/Supports

- Increasing Self Advocacy, Self Empowerment Skills
  - RICC and ARC Self-Advocacy training
  - Peer Support Specialists
  - Peer Mentors
  - Including Self Advocacy curriculum/focus in Skill Building, Clubhouse and Drop-In services

Modifying Services/Supports

- Whole Person Wellness
  - Increasing fun physical activity (especially large muscle group activities)
  - Improving sleep hygiene/patients
  - Increasing healthy eating/choices
  - Practicing mindfulness
  - Smoking Cessation classes/support
    All done to help the individual feel better, not because it’s “good for you”
Modifying Services/Supports

- Creating a Chosen Life
  - Living arrangement
  - Daily activities
  - Community Connections
  - Friends
  - Work/volunteering (structured day)

Modifying Services/Supports to Reduce Perpetration

- Mental Health Recovery Court
  - Diversion program, mostly misdemeanors
  - Voluntary
  - Agree to follow treatment plan
  - Report to court every two weeks with Case Manager
  - Record expunged after successful completion

Jimmy's Story
Jimmy’s Story

• Jimmy is social, chatty, happy person. He loves all things sports related, enjoys the mall and keeping busy.
• Jimmy has some health problems
  • Jimmy works part time at Burger King as greeter and cleaning the lobby

Jimmy’s Story

• From 2001-2013, Jimmy spent as much time hospitalized as in the community
  — Significant periods in Mt. Pleasant Center and Kalamazoo Psychiatric Hospital, and dozens of hospitalizations in community psychiatric hospital, in between multiple failed group home placements
  — Dozens of police contacts, multiple arrests for physical assault and property destruction
  — Multiple ED and medical hospitalizations—not allowing tx and disturbing stoma
• Diagnosed with I/DD, Schizo-affective Disorder, PTSD, suspected Fetal Alcohol Syndrome

Jimmy’s Story

• Started over:
  — Psychiatric re-assessment, reduction in number of medications
  — Apartment with roommate instead of group home
  — Re-trained staff in culture of Gentleness, Culture of Gentleness Mentors in home
  — Completed Biographical Timeline with Jimmy
  — Engaged Jimmy and staff in DBT-modified
  — Got job and volunteering for sports team
What Else Can Be Done?

Accumulation of Risk & Victimization

Childhood Trauma & Abuse
Neuro-developmental dysfunction

Inability to RESPOND to unsafe situation
Unclear communication
Desire to please
Inability to ASSESS safety/situation

Victimization

I/DD Individuals Vulnerable to Victimization

People with disabilities self-reported higher rates of violence than people without disability (National Crime Victim Survey)
- 40 per 1,000 person with disabilities vs. 20 per 1,000 without disabilities

Over 70% of people with disabilities who took the survey reported being victims of abuse (National Survey on Abuse of People with Disability)
...But They Don’t Report

Reason(s) for not reporting
- 58% believed nothing would happen
- 38% had been threatened or were afraid
- 33% did not know how or where to report

...And They Don’t Receive Help

65.4% of victimized I/DD individuals received NO counseling or therapy

Even though it would benefit them
- When provided therapy – 83% said it was helpful to them

Accumulation of Risk & Victimization

- Childhood Trauma & Abuse
- Neuro-developmental dysfunction
- Trauma

Inability to RESPOND to unsafe situation

Unclear communication with authorities

Desire to please

Inability to ASSESS safety / situation

Increased Vulnerability

VICTIMIZATION
WHAT CAN BE DONE: Crime Involvement

- Screen consumers regularly and sensitively for victimization, as well as Post traumatic Stress symptoms
- Staff training to increase awareness of victimization/perpetration and how to spot it
- TREATMENT – PTSD, mental health, substance abuse
- Crime prevention programs to help develop skills that can improve their safety & reduce interpersonal conflict
- Legal advocacy, including connecting victims to community advocacy resources, such as the YWCA Domestic Assault program and Legal Aid
WHAT CAN BE DONE: Healthcare

✓ Healthcare navigators, especially for co-occurring
✓ Integrate health care into criminal justice settings
  ✓ Establish national standards
✓ Provider training
✓ Need more evidence about programming for those with dual diagnosis
  ✓ Including health-related

WHAT DOES THIS MEAN FOR OUR CONSUMERS?

...FOR OUR SERVICES?

...FOR HOW SERVICES ARE DELIVERED?

TRAININGS?

AGENCY PARTNERSHIPS

Integrated services