Lancaster County Plans of Safe Care Symposium 2024



Thank you — Anne Kinderwater Carroll

- Visiting Experts
- Lancaster County Focus Presenters
- POSC Advisory Team
- LGH Community Health Initiatives Team
- S.Dale High Leadership Center

Welcome – Crystal Natan











Presenters

Sandra Kanyamiheto-Watson University of Pittsburgh, School of Social Work The Pennsylvania Child Welfare Resource Center

Michele Walsh, Ph.D., LSW Office of Children, Youth and Families, Pennsylvania Department of Human Services





Objectives

- Define Plans of Safe Care
- Discuss relevant federal and state statues
- Describe how and when to submit a SAI Notification to ChildLine
- Describe the purpose of Plans of Safe Care
- Describe the Plan of Safe Care process lacksquareOutline practice implications including populations served





Plans of Safe Care are for

- Infants (up to 1 year of age) affected by substance use or withdrawal symptoms from prenatal drug exposure, or a Fetal Alcohol Spectrum Disorder and
- Their families and/or caregivers with substance use disorders





CARA (2016), the word "illegal" was removed, and family/caregivers were added to Plans of Safe Care



OR

Withdrawal symptoms resulting from prenatal substance exposure

OR



<u>CARA required:</u>

Health care providers "notify the child protective services systems"...

AND

Development of a plan of safe care for the infant and affected family member or caregiver





Partners in Plans of Safe Care

Department of **Drug and Alcohol** Programs

Department of Health

Department of Human Services





Pennsylvania's Act 54 amended the PA Child Protective Services Law (CPSL) to comply with the CAPTA changes.

"Substance use"

OR

Withdrawal symptoms resulting from prenatal substance exposure

OR

FASD

- Reworks CPSL's Section 6386 to shift from "mandatory reporting" to "notification"
- Notification is for purpose of "assessing" a child and the child's family for a Plan of Safe Care
- Requires PA DHS to collaborate with Department of Health and PA Department of Drug and Alcohol Programs on "written protocols"





Identifying Eligible Infants and Families

Defining "affected by"

Act 54 of 2018

A health care provider shall immediately give notice or cause notice to be given to the department if the provider is involved in the delivery or care of a child under one year of age and the health care provider has determined, based on standards of professional practice, the child was born affected by: (1) substance use or withdrawal symptoms resulting from prenatal drug exposure; or (2) a Fetal Alcohol Spectrum Disorder.

Plan of Safe Care Guidance

Infant up to 1 year of age with detectable physical, developmental, cognitive, or emotional delay or harm that is associated with maternal substance use or withdrawal, as assessed by a health care provider





Five Points of Intervention



Source: A Collaborative Approach to Treatment of Pregnant Women with Opioid Use Disorders

Process to Implement a Plan of Safe Care

Identify Infant & Birthing Person and Educate Person/Family

SAI Notification to ChildLine

disciplinary Team (MDT) (e.g., patient/family, maternal and child health providers, home visiting, SUD providers, mental health providers, agencies, El and developmental services, physical health providers)

Convene Multi-

Develop and Implement Plan of Safe Care (POSC)

Supports for Infant and Mother/Caregiver/Family







Identifying Eligible Infants and Families

SAI **Notification** to PA DHS via ChildLine **Neontal Abstinence** Syndrome (NAS) A separate process: **NAS Report to PA DOH Neontal Opioid** for "Confirmed" NAS Cases Withdrawal Syndrome (NOWS)

pennsylvania DEPARTMENT OF HUMAN SERVICES



Making a SAI Notification to ChildLine

If you have determined this infant was born affected by a substance, provide the information below.

Please Note

A Substance Affected Infant is an infant currently under one year of age identified as born affected by prenatal legal or illegal substance use. "Affected By" is defined as an infant "with detectable physical, developmental, cognitive, or emotional delay or harm that is associated with maternal substance use or withdrawal, as assessed by a health care provider". Please select all substances which apply under the section titled "Substance Affected Infant -Substance Type". Please also identify the birth hospital of the infant. If this is unknown, the unknown indicator may be selected. If you are unsure if the child you are creating this referral on behalf of meets this criteria, please contact ChildLine directly at 1-800-932-0313 to provide the notification.

Substance Affected Infant - Substance Type (Select all that apply)

- Alcohol
- Appropriate use of legally prescribed medication (excluding OUD/SUD Treatment)
- Illegal Substance(s)

- or Opioid Use Disorder
- prescribed)
- Unknown Substance(s)

Substance Affected Infant Birth Hospital

Unknown

Medication Assisted Treatment - Substance Use Disorder

Misuse/Abuse of legal medication (prescribed or un-

ChildLine Service portal https://www.compass. state.pa.us/cwis/public/ home

OR

ChildLine Hotline 1-800-932-0313





Health care provider identifies, at birth or up to 1 year of age, an infant affected by prenatal substance exposure.

Health care provider makes an immediate Notification of a Substance Affected Infant (SAI) is made to Childline (via selfservice portal or hotline)

IO Referral Type Implication for Providers:

Depending on county-level processes and resources the county children and youth agency may contract with a community-based provider for the delivery of plans of safe care.







Development of the Plan of Safe Care

| Substance Type | Potential Entity to Lead the Plan of Safe Care | | | | |
|--|--|--|--|--|--|
| | Prenatal POSC | POSC Development at time of | | | |
| | Development | Birth | | | |
| Opioid Medications for chronic pain or other legal medications that can produce withdrawal symptoms taken as prescribed | Prenatal care provider with pain specialist or another physician | Maternal and child health postpartum service providers, home visiting providers or community-based agencies that provide prevention services | | | |
| Medication-assisted treatment or Medication for Opioid Use Disorder | Prenatal care provider with opioid treatment program or waivered buprenorphine prescriber and/or therapeutic treatment provider | Opioid treatment or therapeutic substance use disorder treatment provider with maternal and child health partners | | | |
| Abuse of prescription medication or use of illegal substances or alcohol use | Prenatal care provider or high-risk pregnancy clinic with substance use treatment provider | County child welfare agency | | | |





Implementation of Plans of Safe Care

- Developing a coordinated, multi-systemic approach to services for Substance Affected Infants (SAI) and their families
- Facilitating access to services for SAI and their families with substance use disorders and other needs
- Monitoring Plans of Safe Care for child welfare involved families

County Child Welfare agencies are tasked with:





Implementation of Plans of Safe Care

***** INFRASTRUCTURE

partners to effectively implement POSC

CATION

families, and the public

PRODUCTS/PURCHASES

support families/caregivers

SERVICES

support participation in POSC

• Fundamental activities needed to support the agency and system

• Training of CCYA staff, system partners, medical providers, SAI

Items provided to SAI families to meet the needs of child and

• Support provided to families and SAI either directly or indirectly to





Innovative County Practices



Fayette County Plans of Safe Care

Plans of Safe Care (POSC) is a free program available for infants affected by prenatal substance exposure and pregnant women struggling with addiction and recovery



Fayette County POSC

Support Session for

GRANDPARENTS RAISING GRANDCHILDREN

March 11, 2024 11am-1pm At the POSC Family Support Center Uniontown Mall by the old Sears store





Innovative County Practices







have complications.

Babies born to women, who use certain prescription medications, illegal drugs, or alcohol can





Resources

- Pennsylvania Act 54 of 2018
- Keep Kids Safe https://www.pa.gov/en/agencies/dhs/resources/keep-kids- safe/about-keep-kids-safe/plans-safe-care.html
- National Center on Substance Abuse and Child Welfare https://ncsacw.acf.hhs.gov/topics/capta-plans-of-safe-care/
- Child Welfare Information Gateway https://www.childwelfare.gov/resources/plans-safe-care-infants-prenatal-substanceexposure-and-their-families/

https://www.legis.state.pa.us/cfdocs/legis/li/uconsCheck.cfm?yr=2018&sessInd=0&act=54







Questions related to POSC?

Contact: RA-PWPLANSOFSAFECARE@pa.gov





Substance Use Data Update in Lancaster County

Ashlee Rineer, MSW, LSW

Project Director, SAMHSA FR-CARA Health Promotion Specialist, Penn Medicine Lancaster General Health

Annual Overdose Deaths in Lancaster County, 2013-present



Updated: May 14, 2024

Sources: Pennsylvania Department of Health Office of Drug Surveillance; Lancaster County Coroner's Office *Note: Data is subject to change and based on reports available to date. Coroner's reports may take 3-6 months to appear in reported data.





Substances Contributing to Cause of Death



Source: Pennsylvania Department of Health, Office of Drug Surveillance Interactive Data Report, OD-Drug Specificity, updated May 20, 2024

■ 2023 ■ 2024





| 0.0 | | | | | | | | | | | |
|------------------|------|------|------|------|------|------|------|------|------|------|------|
| 0.0 | 2012 | 2013 | 2014 | 2015 | 2016 | 2017 | 2018 | 2019 | 2020 | 2021 | 2022 |
| Lancaster County | 12.0 | 10.2 | 13.1 | 15.1 | 22.7 | 32.4 | 22.3 | 20.0 | 27.5 | 27.8 | 22.1 |
| Pennsylvania | 19.3 | 19.8 | 22.1 | 26.4 | 37.2 | 42.9 | 35.4 | 35.0 | 41.3 | 43.0 | 40.7 |
| United States | 14.0 | 14.7 | 15.6 | 17.2 | 20.8 | 22.7 | 21.7 | 22.7 | 29.2 | 33.5 | 33.6 |

Source: CDC WONDER, updated 5/15/2024

Drug Overdose Deaths through December 2023, Lancaster County

12-Month Ending Provisional Counts of Drug Overdose Deaths, Lancaster County



Source: Lancaster County Coroner's Office, updated 5/16/2024

| Jan 2022 | Jan 2023 |
|----------|----------|

December 2022-December 2023: 20.0% decrease







Drug Overdose Deaths through December 2023, Pennsylvania



Source: CDC Provisional Drug Overdose Death Counts, accessed 5/16/24





Drug Overdose Deaths through December 2023, United States



Source: CDC Provisional Drug Overdose Death Counts, accessed 5/16/24





Lancaster County population is 84% White, 4% Black, 11% Hispanic/Latino, and 2% Asian.

Lancaster County population is 8% 18-24, 11-13% for age groups 25-64, and 19% 65+

Source: Lancaster County Coroner's Office (n=12).

Lancaster County population is 49% male and 51% female.



Emergency Department Visits for Opioid Overdose



Source: Pennsylvania ODSMP: Drug Overdose Surveillance Interactive Data Report



Emergency Department Visits for All Drug Overdoses





Source: Pennsylvania ODSMP: Drug Overdose Surveillance Interactive Data Report





Increasing Use of Medication for Opioid Use Disorder



Source: Pennsylvania ODSMP: Drug Overdose Surveillance Interactive Data Report





Food Insecurity and Recovery Nutrition

Elizabeth Hivner, M.ED, CHES Manager Community Health and Wellness

Carly Kessler, MPH, RDN, LDN Community Health Dietitian

Introduction

- from.
- Relevance
- Presentation Overview
 - Landscape of Food Insecurity Nationally •
 - Local Food Insecurity ٠
 - **Current Food Access Initiatives** •
 - Nutrition and Recovery •
 - Disordered Eating and Eating Disorders ٠
 - Plans of Safe Care •
 - Questions and Comments •

Food Insecurity - when people don't have enough to eat and don't know where their next meal will come


Food Insecurity Nationally

Data

- How do we compare to other 1st world countries? ٠
- Contributors housing, income, etc
- Impacts/costs of food insecurity on individuals and systems



Food Insecurity

WA MT OR ID WY NV UT CA CO AZ NM 10 HI AK

significantly different from the U.S. average. Security Supplements.





A Downward Cycle

Poor Disease Management





Food Insecurity and Children

- Food-insecure children are twice as likely to report poor health compared to foodsecure children and have increased risk of:
 - anemia
 - cognitive problems
 - aggression ۲
 - depression and anxiety
 - asthma ٠
 - poor oral health
 - increased risk of being hospitalized •



This Photo by Unknown author is licensed under <u>CC BY</u>.



Percentage of Children with Food Insecurity

Lancaster Pennsylvania



Source: Feeding America, accessed from Ighealth.org/countyhealthdata and map.feedingamerica.org Updated: 7/7/2023

Created By: Brenda Buescher, MPH (brenda.buescher@pennmedicine.upenn.edu)



Food Insecurity in Lancaster County

- Over 40K individuals in Lancaster county are food insecure Our hospital was serving approximately 4,000-5,000 food insecure patients each year Certain groups are more likely to be insecure:
 - households with children
 - Especially those headed by single women
 - Lower-income
 - African American and Hispanic or Latino households ۲





Food Insecurity in Lancaster County

by Census Tract





Percentage of Adults with Food Insecurity



Source: Feeding America, accessed from Ighealth.org/countyhealthdata and map.feedingamerica.org Updated: 7/7/2023

Created By: Brenda Buescher, MPH (brenda.buescher@pennmedicine.upenn.edu)



Lancaster Programs

- Fresh Express
- Food Pantries over 40
- Food Farmacy Program at:
 - The Food Hub •
 - The Factory Ministries ٠
 - Elizabethtown Community Cupboard ٠
 - Columbia Dream Center
 - Solanco Neighborhood Ministries •
 - Ephrata Area Social Services •
- WIC & after school meal programs Facilitated by Community Action Partnership

- Meals on Wheels
- Free Community Meals



Nutrition Therapy

- Essential in improving neuroplasticity
- Assists the brain in replenishing neurotransmitters
- Assists in tissue and organ repair
- Improves immune defenses
- Increases energy
- Improves mood

Source: Jeynes KD, Gibson EL. The Importance of Nutrition in Aiding in Recovery from Substance Use Disorders: A Review. 2017



Nutrition Quality

- Quality matters
- Carbohydrates
- Amino Acids
- Dietary Fat
 - Omega 3
 - Omega 6

Vitamins and Minerals

Source: Today's Dietitian CEU, accessed from https://www.todaysdietitian.com/newarchives/120914p44.shtml Source: Gateway Foundation, accessed from https://www.gatewayfoundation.org/addiction-blog/nutrition-for-substance-abuse-recovery/





Barriers to adequate nutrition

- Loss of appetite
- GI disorders
- Cravings poor dietary choices
- Nausea/vomiting
- Organ damage
- Hypoglycemia
- Food insecurity
- Eating disorders



Eating Disorders and Disordered Eating

Eating disorder

OSFED, Pica, rumination disorder)

Disordered eating

- Dieting, skipping meals, distorted body image
- not fully met



Source: Emory Counseling Services, accessed from https://counseling.emory.edu/resources/body-image-eating-disorders.html

Clinical diagnosis based on DSM5 criteria (anorexia nervosa, bulimia nervosa, binge eating disorders, ARFID,

Often includes components of an eating disorder but actions may be less frequent or clinical diagnosis has not been

The Spectrum of Eating Behavior

Disordered Eating

- · Difficulty with reading body's cues of
- hunger & fullness
- In and out of diet trends
- Firm dietary restrictions
- · Incorporates restriction in their
- relationship with food
- Eats or restricts to regulate emotions or the environment
- Has more negative body image days than positive ones
- Inflexible with their variety of foods
- Engages in movement to make up
- for caloric intake

Eating Disorder

- Anorexia Nervosa (AN)
- Bulimia Nervosa (BN)
- Binge Eating Disorder (BED)
- Avoidant and Restrictive Food Intake Disorder (ARFID)
- Eating Disorders Not Otherwise Specified (EDNOS)
- Diabulimia
- Orthorexia



Eating Disorders and Disordered Eating

50% of individuals living with an eating disorder are also impacted by substance use

Nutrition counseling should be individualized

- Comprehensive nutrition assessment that identifies food behaviors and beliefs ٠
- Appropriate interventions for individuals impacted by eating disorders or disordered eating ۲



POSC Nutrition Counseling and Health Coaching

NEW grant-funded program

Personalized communication and nutrition counseling to individuals who initially declined POSC involvement.

Purpose

- Provide health coaching and nutrition counseling to assist individuals with their overall health.
- Manage cravings and withdrawal symptoms that might affect parent and baby.
- Determine level of parent readiness and assess obstacles to participation in POSC or other support services for themselves and their child.



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POSC Nutrition Counseling and Health Coaching

Started April 2024

Minimum of 2 sessions with a Registered Dietitian

- Initial intake- identify concerns and create goals ٠
- Follow-up-review goals, discuss progress/barriers, include grocery shopping/grocery store tour •
- Referrals from Early Intervention Tracking Program
- Capacity to expand





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Thank you!

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BREAK – 15 minutes





Early Intervention Data in Lancaster County

Angel Deputy Directo Lancaster County Behavio

Angela Schreck

Deputy Director, Early Intervention

Lancaster County Behavioral Health Development Services

Number of Referrals by Source 22-23

| Other | 1 | | | | |
|-----------------------------|---|----|----|----|---|
| Vantage House | 7 | | | | |
| Other Social Service Agency | | | | | |
| STEPS | 4 | | | | |
| Other County El Program | | | | | |
| CONNECT | 1 | | | | |
| Kinship/Foster Parent | 3 | | | | |
| Physician | 5 | | | | |
| Hospital/NICU | | | | 31 | |
| Children and Youth Agency | | | | | 4 |
| | 0 | 10 | 20 | 30 | 4 |



- Physician
- Kinship/Foster Parent
- CONNECT
- Other County El Program
- STEPS
- Other Social Service Agency
- Vantage House
- Other



Children and Youth Agency

438

Hospital/NICU

318



Secondary Referral Reason 22-23





Referrals Reporting Substance Use 22/23



MAT Reported 22/23





Placement at Time of Referral 22/23



Outcome of Referral 22/23



RECEIVING ONGOING SERVICES

ENROLLED IN TRACKING



| 29 | | |
|----|---|--|
| | | |
| | | |
| | | |
| | 9 | |
| | | |

REFERRAL WITHDRAWN

NOT ELIGIBLE/DECLINED TRACKING

Services Received Following Initial Evaluation 22/23

ST, SI OT, ST, SW OT, PT, SI,... OT, PT, SI OT, PT, SW OT, PT PT Only OT Only





2024 El Referral Data (n=50)

Referral Withdrawn

Not Eligible for Ongoing Services- Enrolled inTracking

Not Eligible- Declined Tracking

Eligible at Evaluation for Ongoing Services

No Evaluation- Enrolled in Tracking

Out of County Transfer

Pending Evaluations

Referrals-Intake





What is Happening NOW(s)? Barbara Chaiyachati, MD, PhD Valerie Martin, DO





• PennMedicine



https://www.papqc.org/initiatives/sen





Neonatal Follow-up Program

Resilience After Infant Substance Exposure (RISE) Program





Barbara H. Chaiyachati, MD, PhD





Neonatal Follow-up Program

Resilience After Infant Substance Exposure (RISE) Program





Barbara H. Chaiyachati, MD, PhD

Children's Hospital of Philadelphia[®]





Presenter Disclosures

| Funding | BHC: NIMH K08 (PI) |
|---------|------------------------------------|
| | BHC: NIH HEALthy Brain Child Deve |
| | BHC: Delaware County Opioid Settle |
| | |

Resilience After Infant Substance Exposure (RISE) Program





Barbara H. Chaiyachati, MD, PhD

elopment (Site Col) ement (NFP-RISE)







What is Happening NOW(s)?



Objectives

- List the benefits of non-pharmacological therapy for infants with NOWS
- Describe the local trend in outpatient follow up for infants with NOWS
- Analyze what is known about long term outcomes with ESC
- Discuss recovery informed care

NOWS Treatment Models

The NEW ENGLAND JOURNAL of MEDICINE

Eat, Sleep, Console Approach or Usual Care for Neonatal Opioid Withdrawal



RESEARCH SUMMARY

Young LW et al. 2023



NOWS Treatment Models

- •Function based assessment
- •Nonpharmacological interventions
- •Empowerment of families/caregivers



VS.

•Subjective, observer-rated scale •Pharmacological interventions

Young LW et al. 2023





ESC Benefits (Nationally)

Decreases the initial length of stay

Time from Birth to Medical Readiness for Discharge



14.9 (95% CI, 13.1 to 16.7) Absolute difference, 6.7 days (95% CI, 4.7 to 8.8) Rate ratio, 0.55 (95% CI, 0.46 to 0.65) P<0.001

Usual Care

Young LW et al. 2023


ESC Benefits (Nationally)

- Decreases the initial length of stay
- Decreases pharmacological therapy
- Removes barriers to breast feeding

Young LW et al. 2023



ESC Benefits (Nationally)

- Decreases the initial length of stay
- Decreases pharmacological therapy
- Removes barriers to breast feeding





Composite Safety Outcome

Young LW et al. 2023



ESC Implementation in Lancaster

 In February 2021, Women & Babies implemented Eat, Sleep Console



https://www.pennmedicine.org/news/internal-newsletters/the-lgexperience/2022/january/eat-sleep-console-a-better-way-tohelp-newborns-in-withdrawal



- Decreased separation of Mother/infant dyad
- Decreased average length of stay
- Decreased use of pharmacological treatment

Decreased separation of Mother/infant dyad

Percentage of Infants with Perinatal Opioid Exposure Admitted to the NICU



- Decreased separation of Mother/infant dyad
- Decreased average length of stay



Average Length of Stay for Infants with Perinatal Opioid Exposure

- Decreased separation of Mother/infant dyad
- Decreased average length of stay
- Decreased use of pharmacological treatment



Outpatient Follow Up After ESC (Locally)



Neonatal Follow-up Program

- Eligibility criteria: pharmacological therapy for 30 days
- 3 patients in 5 years have come to the Neonatal Follow Up Clinic

Outpatient Follow Up

- Increased risk of mortality
- Higher rate of emergency department visits
- Higher rate of hospital admissions
- Lower rate of well-child visits
- Lower rate of developmental follow up services

Mascarenhas et al. 2024



NOWS Long Term Outcomes: School Age

- Delays in motor and cognitive outcomes in preschool aged children
- school-aged children

Increased risk for attention-deficit/hyperactivity disorder in pre-school and

Mascarenhas et al. 2024



Comparison of outpatient outcomes between "usual care" and ESC

Trials. 2022; 23: 638.

Published online 2022 Aug 9. doi: <u>10.1186/s13063-022-06445-z</u>

Eating, Sleeping, Consoling for Neonatal Opioid Withdrawal (ESC-NOW): a Function-Based Assessment and Management Approach study protocol for a multi-center, steppedwedge randomized controlled trial

Leslie W. Young,¹¹ Songthip Ounpraseuth,² Stephanie L. Merhar,³ Alan E. Simon,⁴ Abhik Das,⁵ Rachel G. Greenberg,⁶ Rosemary D. Higgins,⁷ Jeannette Lee,⁸ Brenda B. Poindexter,⁹ P. Brian Smith,⁶ Michele Walsh,¹⁰ Jessica Snowden,¹¹ Lori A. Devlin,¹² and for the Eunice Kennedy Shriver National Institute of Child Health and Human Development Neonatal Research Network and the NIH Environmental influences on Child Health Outcomes (ECHO) Program Institutional Development Awards States Pediatric Clinical Trials Network

What is Next?

PMCID: PMC9361241 PMID: 35945598

- Compare children with and without opioid exposure:
 - Brain structure

 - Medical, developmental, and behavioral outcomes Environmental and parenting modifiers in neurodevelopment

What is Next?

- Compare children with and without opioid exposure:
 - Brain structure

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> Pediatr Res. 2023 May;93(6):1772-1779. doi: 10.1038/s41390-022-02279-2. Epub 2022 Aug 30.

Outcomes of Babies with Opioid Exposure (OBOE): protocol of a prospective longitudinal cohort study

Carla M Bann¹, Jamie E Newman², Brenda Poindexter³, Katherine Okoniewski², Sara DeMauro⁴, Scott A Lorch⁴, <u>Deanne Wilson-Costello⁵</u>, Namasivayam Ambalavanan⁶, Myriam Peralta-Carcelen⁶, Catherine Limperopoulos⁷, Kushal Kapse⁷, Jonathan M Davis⁸, Michele Walsh⁹, Stephanie Merhar¹⁰

Affiliations + expand PMID: 36042329 PMCID: PMC9971338 DOI: 10.1038/s41390-022-02279-2

What is Next?

- Compare children with and without opioid exposure:
 - Brain structure

 - Medical, developmental, and behavioral outcomes Environmental and parenting modifiers in neurodevelopment



HEALthy Brain and Child Development Study (HBCD)



HEALthy Brain and Child Development Babies · Brains · Bright Futures

What is Next?

https://hbcdstudy.org/



Unknown Long Term Outcomes

- The complexity of the mother-infant dyad after discharge
 - Food/housing insecurity
 - Psychiatric disorders
 - Foster care/Other caregiver care
 - Early intervention strategies
- School aged data and outcomes

Singh R et al. 2024



What Now?

Recovery Informed Care

- Compassionate care
- Informed
- Recovery

• From a family vantage



Compassionate Care: Identification of Substance Use Disorder

- Requires disclosure
 - Disclosure requires trust
 - Trust is hard when there is fear
 - Hence compassionate care interactions



Compassionate Care: A first step: Non-stigmatizing Language

FROM THE AMERICAN ACADEMY OF PEDIATRICS | POLICY STATEMENTS | MAY 23 2022

Recommended Terminology for Substance Use Disorders in the Care of Children, Adolescents, Young Adults, and Families 🔗

Rachel H. Alinsky, MD, MPH, FAAP; Scott E. Hadland, MD, MPH, MS, FAAP; Joanna Quigley, MD, FAAP; Stephen W. Patrick, MD, MPH, MS, FAAP; COMMITTEE ON SUBSTANCE USE AND PREVENTION Pediatrics (2022) 149 (6): e2022057529. https://doi.org/10.1542/peds.2022-057529

families affected by substance use."

• "Pediatricians ... actively working to dismiss harmful stereotypes and avoiding the use of stigmatizing language in favor of medically accurate terminology that respects the dignity and personhood of individuals with substance use disorders and the children and adolescents raised in



Person with/diagnosed with opioid use disorder person who uses or injects substances

Addict User Suffering from addiction

> Person in recovery **Person who stopped** using substances

Image Source: American Academy of Pediatrics



Content Knowledge: Identification of substance use disorder

- Substance use disorder is a medical diagnosis
 - Aspects are relevant to care interaction of infants
- Potential manifestations of SUD exposure in infancy
 - Physical examination
 - Neurodevelopmental
 - Differential diagnosis
 - Epidemiologic associates with many confounds



Content Knowledge: Differences are not in isolation

- Environmental contexts that may have high stimulatory burden
- Caregiver dyad with potential for altered response/reward processing
 - SUD with changes to neurocircuitry
 - Some shared response/reward pathways between new parenting & SUD
 - Differences in brain activation to parenting stimuli
 - Overall: Increased salience of stress, decreased rewards of parenting

Landi et al. Frontier Psychiatry, 2011. Light et al, Addict Behavior, 2004. Rutherford et al, Frontier Psychiatry, 2011.



Recognition of Recovery Journey: Recovery Journey



https://www.addictionpolicy.org

Recognition of Recovery Journey: And beyond

Patient Experience Journey Map

The Addiction Policy Forum Patient Journey Map represents a common set of moments that individuals in treatment and recovery from a substance use disorder experience. While this map does not represent what happens to every individual who engages in treatment for addiction and recovery support, it highlights common elements and bright spots and pain points in accessing care and finding and maintaining long-term recovery. Quotes from patients are included to illustrate the salience of the moment. Common threads and insights are also provided, which can guide practitioners and leaders in the improvement of care and patient outcomes for individuals with a substance use disorder.

| Onset & Progression | Phase | Trigger Events | | | Getting Help | | | | Care Begins | | | Treatment & Recovery | | | | | Lifestyle Changes | | | | | Ongoing Support | | | |
|---|--------------------|---|--|---|--|--|---|---|---|---|--|---|--|--|--|--|---|---|--|--|--|--|--|---|---|
| Average Initiation of Substance Use is 14 years old The earliest age of first use reported was 5 years old; the latest was 19. | Common Threads | Patients report multiple trigger events with the most prevalent reason for engaging in treatment being tired/wanting change (87%), followed by health reasons (35%), pressure from loved ones (23%), parenting/custody concerns (22%), and pressure from the criminal justice system (20%). | | | | Poor treatment access was a common experience among participants who experienced systemic barriers to addiction care, including high levels of stigma (32%); the complexity of navigating the substance use disorders care system (25%); wait times (20%); the high costs of treatment (8%); red tape payer policies such as fail first and prior authorization (7%); and transportation difficulties (5%). | | | | Direct engagement with a specialized treatment provider was the most often utilized first point of contact to find help (37%), followed by hospital or emergency room (20%), doctors (15%), mental health provider/counselor (7%), and criminal justice agencies (3%). | | | On average, patients utilized four different services for treatment and recovery support, not a single treatment or intervention. Services accessed were support groups (88%), counseling/mental health treatment (57%), intensive outpatient treatment programs (52%), followed by residential programs (37%), aftercare programs (30%), medications for addiction treatment (28%), sober living (22%), and faith-based programs (12%). | | | | Common lifestyle modifications include avoidance of high-risk people, places, and things (42%), changing friends (40%), becoming honest open minded and accountable (25%), self- care such as exercise, nutrition, and sleep (23%), and developing a consistent routine (13%). | | | | | On average patients utilize three services for ongoing support. The most common services were support groups (67%), family and friends (55%), volunteer and service work (38%), and mental health/counseling (22%). | | | |
| 85% Report Family History of SUD 85% report a family history of substance use disorders. Patients report an average of 2 previous generations of SUD history. | Journey Details | Tired/ Want Change | Health Reasons/ Injury | Pressure from Loved Ones | Parenting/ Custody | Looked for Treatment Directly | Talked to a Loved One/Friend | Looked for Support Group | Talked to Mental Health Professional | Treatment Facility First Point of Contact | Co-Occurring Disorders Prevalent | Trauma Experienced During Active Addiction | Support Groups | Counseling/ Mental Health | Intensive Outpatient Program | Medications for Addiction Treatment | Aftercare Program | Avoiding Risky People, Places, and Things | New Friends | Honesty and Accountability | Selfcare: Exercise, Nutrition, Sleep | Routine/ Management Plan | Support Groups | Volunteering & Community Service | Mental Health/ Counseling |
| Polysubstance Use Prevalent Image: State in the state in | | "I just was desperate I didn't want to use anything anymore, I was tired." | "I was doing like over three grams a day by myself and I was still sick all the time in withdrawal, no matter how much I did." | "[My Dad's friend] told me you don't always have to live like this and it kind of planted the seed, that's all he said to me." | "I wanted to reunify with my children, and I was sick and tired of being sick and tired." | "I researched the methadone clinic and decided that that was probably what I needed to do." | "I reached out to my probation officer and said I need help and he put me into a residential treatment center." | "I went to a ton of meetings, I went to three meetings a day, or more, just completely immersed myself in the recovery community". | "I went to see the therapist and they put me in the hospital." | Previous experiences and treatment episodes guide the first contact and research conducted by patients when selecting treatment. | 67% have a co- occurring mental health disorder, Depression, anxiety disorder, and bipolar disorder are the most common diagnoses, | Trauma often experienced during active addiction, including physical violence and sexual assault. | "Another bright spot was the camaraderie of the program, that was really amazing to me, I was so shocked to see all the people in there, I never had any idea." | "It took someone like that therapist that never gave up on me, that kept working with me to reel me back into realities." | "Intensive outpatient you really learn about the disease. You see a lot of people that are struggling." | "They got me into the methadone clinic. So then, I had a counselor at the methadone clinic, my case manager, and my recovery coach." | "Our aftercare program is two years, so you get to know peopleit provided a sense of community or a support system." | "Well I moved, out of state, changed my people, places and things, changed routine and old habits, changed things that I did in my spare time." | "I had to change the people that I associated with and talk to in my life, I literally had to move away from my home to get sober." | "I had to be honest with myself and my family about my addiction, because I kept that a secret for a long time. I had to let them in." | "I started changing my health. I started working out more often and eating better. Just kind of taking care of myself." | "Finding some kind of routine, that was hard. " | "Lactually enjoy going to my meetings now, they're a part of my day, I go to meetings every day," | "I go every month back to the homeless shelter. That's one of my biggest joys getting to share my inspiration with other people." | "So my therapist is huge in my recovery." |
| Over 83% experienced household dysfunction, 78% experienced abuse, and 55% suffered from neglect. Hospitalization Image: The second s | O _{Spots} | Children & Family "I didn't want to be separated from my daughter again and risk that being the cycle of her seeing me in and out of prison all throughout her life." | Relief "It was just like relief I'm finally going to go do this." | Hope for Change "Knowing that I was turning a new leaf and knowing that I was going from a very negative outlook and existence to looking forward to a very positive one." | Encouragement from Others "My pastor called. When I told him I was going to get help and he was like I'm glad you did that. But that was the only bright spot." | Friends/Family Recovery "Well, my brother was in recovery, so I at least knew someone and didn't completely feel alone at that point." | Not Alone "I was no longer alone, because I was in a group setting, so the loneliness dissipated." | Smooth Transition "After the assessment I didn't have to wait a very long time. I think there was a sense of relief if that makes sense." | Finding a Community Tistarted realizing that there's a lot of people in my community who are sober." | Friendly, Engaging Staff "So there were people along the way that were just kind, and sometimes that was all it took." | Employment/ Housing 'I mean, I had a roof over my head. And I had a part time job. And I had the support of my family.' | Peers/Recovery Coaches "I think, for me, what kind of helped was the gentleman that I met at that treatment Center doorand he shared his experience with me. I identified with him." | Positive Social Connections "The social aspect of it because your first couple of years of recovery can be lonely because everyone you know you had to cut out of your life." | Helpful Clinicians "The counselors call and check on you. The doctor calls and checks on you, even thoughit's not as often, but yearly he calls to see how you're doing " | New Tools and Skills "You just learn how to deal with it, the tools that can help you to stay sober." | Learning about the Disease "It was amazing You realize you're not alone and you realize that it's, it really is a disease, and that you don't have to do it alone." | Peer/Recovery Coach "My counselor for sure at treatment, she was actually in recovery herself and she really helped me." | Reunited with Children/Family 'Just being clean again, having goals again, being around people that lloved and that loved me was really healing. Just being clean, just delicious, it's wonderful." | Friendships/ Support Network "Sense of belonging, getting to know a good group of people or community." | Feeling Happy Again "Finding joy and the excitement to know that I do have a purpose and the possibilities are infinite." | Being Present in Life Again "It was appreciating things that I didn't appreciate for a long time, things like being outside and the nice weather and hearing the birds singing" | Physically Healthier "I feel like the changes that I made were just kind of self- care as far as like going to therapyeating healthy, doing exercise, you know, taking care of myself talking to a spensor, doing step work." | Having a Full Life "Thave full custedy of my daughterI bought a house, I'm gainfully employed, I can drive a vehicle legallyfriends, family." | Feeling of Accomplishment "This feeling of worth and a feeling of accomplishme nt for what I've doneit makes you feel good about yourself." | Healthy Relationships "Restoration with my oldest daughter, just closer relationship with my dad and youngest daughter, just an overall feeling of relief and health and gratitude." |
| Coverdose Coverdose | Points | "I was in jail, I Was away from my kids, it was scary." | "Just so much shame. The word doesn't even encapsulate what that feels like you know. I had utter hatred for myself." | Lost Relationships "I lost all my family, I had nothing to my name anymore, I finally realized the people that I was with did not care about me in the least bit. Yeah, I had nothing." | *Not knowing if I could do it, or like what my life would be like, if I entered recovery.* | Waiting for Access "The wait, the wait time is long. I was in withdrawal, so the desire to leave and go, you know get well, was really strong." | Withdrawal Symptoms "It was very difficult, the withdrawing and not being able to use because I couldn't [take a] hit." | Not Finding Help "So in my experience, I was not able to get help when I needed it or when I asked for it." | Navigating Insurance 'I found it to be difficult navigating the insurance. And there wasn't a lot of choices, there wasn't enough beds." | Difficulty Repeating History "The reliving my bottorn, having to constantly re- discuss itwas probably the roughest point of the assessments." | Isolation "I still was living in my car. And I really thought that by signing myself into treatment that (my parents) would let me come home and that didn't happen." | Feeling Stigmatized "Well, I definitely felt stigma, I definitely felt [the assessment] was long, it was way too many questions, it was like being interrogated. I just didn't have the mental capacity to endure that at that time because I felt so defeated and beat up and ashamed and guilty." | Hard Work/ Difficulty "It was hard and a lot of work, I mean just the honesty that's required and being honest with myself. I had a problem, but really confronting it doing something about it was what's difficult." | Managing Shame/Self Stigma 'Facing the past, walking through the things overcoming my identity and how I saw myself and pushing through those things were very painful, it still is every day.' | Cutting out Friends/Old Network "The most painful thing in the beginning, was that I lost people I thought were very close to me and really cared about me. So the painfulness was the realization that drugs are what bound me to a lot of people." | Transportation Challenges "Riding the bus- I had to take two buses to get there. Sometimes, it was a long day to go to work and then go to treatment and sometimes I was super tired." | Unhelpful Home/Work Environment 'I was in intensive outpatient so it was difficult to be going home or working in an environment where you know, drugs and alcohol were present, you know, So that was challenging, just feeling triggered." | Sadness/ Depression "Man I dealt with a lot of mental health stuffilike severe depression and suididal thoughts and stuff like that. It wasn't pleasant at all." | Triggers: People, Places & Things "Knowing people, places and things were a huge part of my recovery, as well as knowing that if I wanted to be in recovery and stay in recovery, I had to cut a lot of people out of my life and make better choices." | Difficulty Making Amends "Dealing with the consequences of things that I did in my addiction and cleaning up the mess that I made. The trust within my house- my family didn't trust me at all." | Trouble Sleeping "Icouldn't sleep anymore, I was so uncomfortable. I remember just kicking around in my bed for hours and hours and hours, and that was really painful." | MAT Stigma "I guess stigma from other people for being on a MAT. I went to my family doctor and they wouldn't even entertain anything else other than getting off the methadone." | Health Consequences | COVID "Challenges include obviously the COVID bring. I don't want to go to meetings in person, because the people that are in person don't seem to care about COVID." | Limited Access to Services "In this rural area I'm finding support groups are very limited and if you're a multiple pathway person it's even more limited." |
| Financial Problems Personality Changed Homelessness | Insights | On average, patient shared three separate trigger events that contributed to engaging in treatment, a cluster of events that constitute the Aha moment. The events weren't necessarily close in timing, but represented meaningful moments for the patient. | | | | The accessing help phase is often identified by patients as extremely painful, disorganized and difficult. Previous treatment and recovery experiences, along with recommendations from friends, family and a person's network frequently form the basis for the treatment pathway selected. | | | | Repetitive assessments and interviews during the care phase were a consistent difficulty among patients with reports of feeling triggered and interrogated. Patients also questioned the utility of multiple interviews and the coordination of providers. | | | Patients report that previous treatment episodes provided a foundation for treatment and recovery success. Rather than viewing previous episodes as failures, the skills and tools learned accumulated over time. Patient feedback also shows the need for layered interventions across three critical domains: 1) biological, or physical health, 2) psychological, and 3) social. | | | | | Patients share that the things encountered every day play a critical role in supporting or hampering recovery. Building a positive, supportive social network is a dominant feature of successful recovery, along with avoiding individuals, places and other triggers that present memory and physical cues to resuming substance use (i.e. using friends, bars, parties, concerts, boredom.) The exact constellation of triggers is unique to each patient. | | | | | Patients sustain ongoing support specific to their needs for years or even decades. Family/friends, service to others and support group attendance are the most significant components identified by patients. | | |

https://www.addictionpolicy.org

Recognition of Recovery Journey: Trigger event: Child Protective Services

- Nationally, punitive approach associated with non-desired care trajectories
 - Lower engagement in pregnancy care
 - Austin, Naumman, & Simmons, JAMA Pediatrics, 2022
 - Lower representation in treatment
 - Kozhimannil, et al, Addictive Behaviors, 2019

Recognition of Recovery Journey: Trigger event: Child Protective Services

Just as being trauma-informed does not abdicate our responsibility as mandatory reporters if a child is harmed by a traumatized caregiver, nonstigmatizing, recovery-informed care is not providing blanket acceptance of dangerous caregiver substance use that results in harm to a child but it does push us to recognize substance use disorder as a medical diagnosis with the potential for recovery, not a moral failing exclusionary from safe parenting.

Recognition of Recovery Journey: CPS Considerations

- Accuracy
- Closed loop communications
- Transparency

Conclusion

- ESC has decreased length of stay, pharmacological therapy, and separation of infant/mother dyad
- Outpatient follow up for infant's with NOWS has barriers
- Current research is trying to understand NOWS non-pharmacological therapies and the long term impact
- Recovery is a journey

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LUNCH–45 minutes

CONNECT

and

Your Assignment...

- roles
- Share what morning's takeaways confirmed your practice
- Determine what, if any of the morning's shared information may shift your practice, approach, connection

Connect with colleagues across organizations, similar

What Happens NEXT?

24/25 FY Grant includes:

- systems.
- Expanding recovery nutrition outreach
- vear

Building secure, confidential communication between

Build pathways from prenatal/postnatal to beyond first

Requests – Now and Later

If you wish to request materials in any quantity, please reach out.

Totes, books, POSC materials, NOWs Directory Lock boxes

Narcan Naloxone training

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