

Supported Decision Making Panel

9/19/2022



PENNSYLVANIA
DEVELOPMENTAL
DISABILITIES
COUNCIL

Our Speakers



- Max Barrows is Outreach Director for Green Mountain Self-Advocates
- Laura Butler, MRC, MA, cofounder of My Choice Kentucky, works at The Human Development Institute at the University of Kentucky
- Morgan K. Whitlatch, J.D., is the Director of Supported Decision-Making (SDM) Initiatives at the Center for Public Representation



Center for Public Representation

Supported Decision-Making: Overview & Update on U.S. Trends

Morgan Whitlatch, J.D.
Director of Supported Decision-Making Initiatives
Center for Public Representation

www.supporteddecisions.org

<https://centerforpublicrep.org>

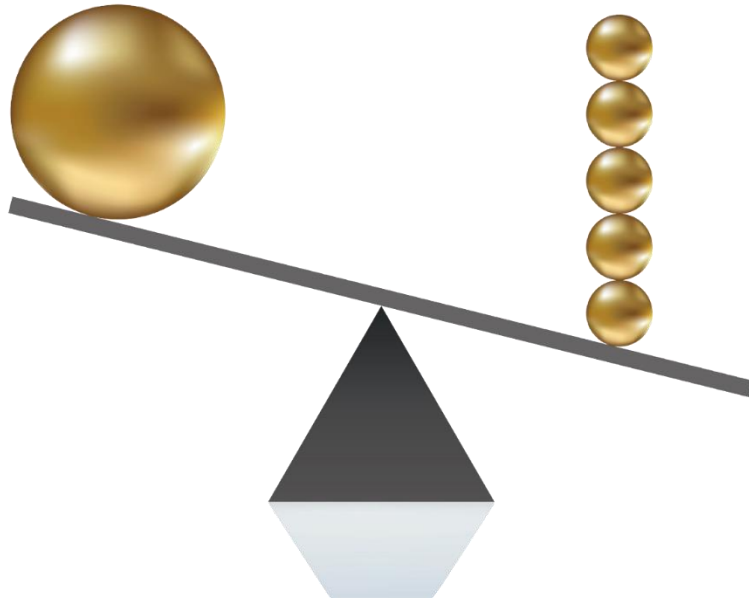
Center for Public Representation

- A leading **national legal advocacy center** in the United States for over 40 years
- Work on **supported decision-making** extends to **pilot projects, training, technical assistance, resource development**, and other collaborations
- Current areas of **special focus** include supported decision-making in **medical care** and with **youth**
- Offices in Massachusetts, New York, and Washington, D.C.



- National resource center founded in Fall 2020 through a five-year grant from the Administration on Community Living
- Supports State Teams in promoting alternatives to guardianship for youth with intellectual or developmental disabilities
- Promotes youth leadership in all levels of its work
- <https://youth-voice.org>

How much do **YOU** know about
Supported Decision-Making?



What is “Supported Decision-Making”?



- It is a **way of making decisions** that people with disabilities can use.
- You work with **people you choose** to **help you** understand your choices and **make your own decisions**.
- The people who give you help making decisions are called **your supporters**.
- **You are the decision-maker.**

Common Questions about Supported Decision-Making

- Who can use it?
- Is it new?
- How is it different than guardianship?
- Is it really legal?
- Is it safe?



Why Use Supported Decision-Making?

- ▶ **Self-Determination**
 - ▶ **Life control** — People's ability and opportunity to be actors in their own lives
- ▶ **People with disabilities with greater self-determination are:**
 - ▶ More **independent**
 - ▶ More **integrated** into their communities
 - ▶ **Healthier**
 - ▶ Better able to **recognize and resist abuse**



Some Findings from the CPR SDM Pilots

- Decision-makers **did not** experience abuse, neglect, or financial exploitation through use of SDM
 - Chose supporters they trusted
 - Multiple supporters



- Decision-makers reported **increases** in:
 - **Pride**
 - **Self-confidence**
 - **Happiness**
 - Willingness to **try new experiences**
 - Taking **greater control** of their health and mental health care

Supported Decision-Making: Why?

- ▶ **People with intellectual and developmental disabilities** without a guardian are more likely to:
 - **Live in their own homes or apartments**
 - Be **included in the community**
 - Have their **rights respected**
 - Have **community jobs or service plans** with that goal
 - Be **supported to communicate** with friends
 - Be **involved in making choices** about their own lives.
 - Bradley et al., National Core Indicator Data Brief, 2019



Common Questions about Using Supported Decision-Making

- ▶ **How do I get started?**
- ▶ **Who can be a supporter?**
- ▶ **Do I need a lawyer?**
- ▶ **Do I need to use a special form?**
- ▶ **What if my supporter and I disagree?**



More in the SDM “Toolbox”

▶ **Supported Decision-Making Guides**

- ▶ Visit <https://supporteddecisions.org>
- ▶ Visit <https://gmsavt.org/resource-library>

▶ **Planning and Practice**

- ▶ Vision or Dream Boards
- ▶ Release of information Forms (“HIPAA” or “FERPA”)
- ▶ Advance Planning Tools
- ▶ Model Forms

▶ **U.S. Federal Law**

- ▶ Americans with Disabilities Act
- ▶ Rehabilitation Act



Looking Nationally...

- **U.S. Administration for Community Living** ([2014 to present](#))
- **National Guardianship Association** ([2016](#))
- **Social Security Advisory Board** ([2016](#))
- **AAIDD & The Arc of the U.S.** ([2016](#))
- **American Bar Association** ([2016](#) & [2017](#))
- **Uniform Law Commission** ([2017](#))
- **U.S. Dept. of Education** (2017, [2020](#))
- **National Council on Disability** ([2018](#) & [2019](#))
- **Center for Youth Voice, Youth Choice** ([2020 to present](#))
- **Fourth National Guardianship Summit** ([2021](#))
- **U.S. Senate Committee on the Judiciary, Subcommittee on Constitution** ([2021](#))





Thank you!

For more information on
supported decision-
making and CPR's pilots:

<https://supporteddecisions.org>

mwhitlatch@cpr-ma.org

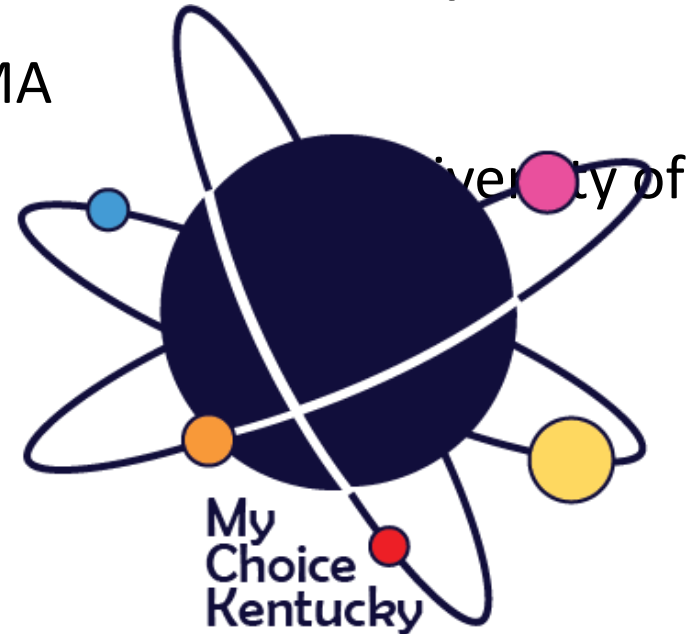
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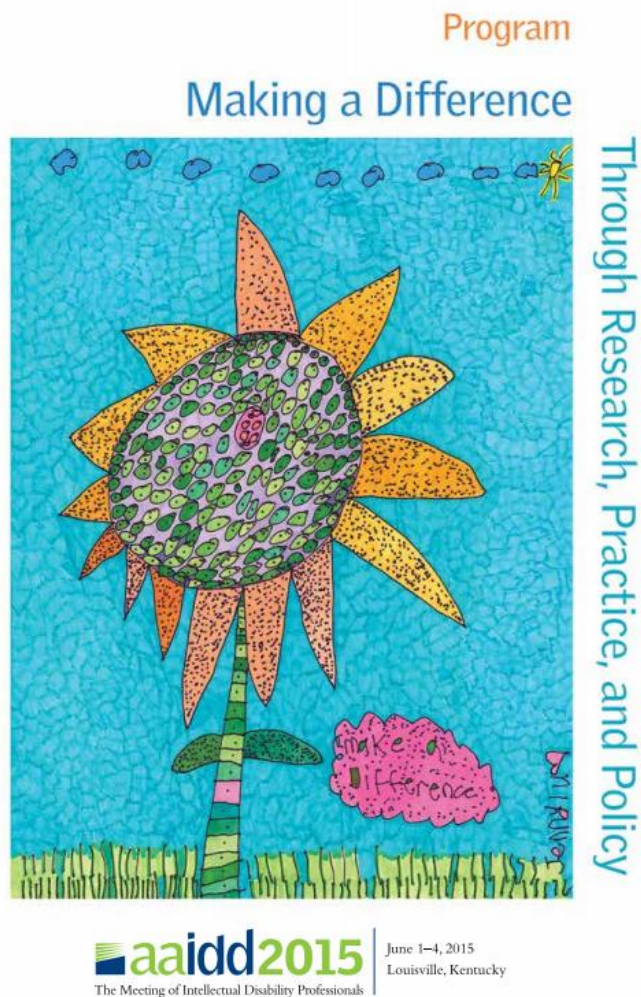
My Choice Kentucky: Grassroots efforts to expand supported decision-making in Kentucky

Laura Butler, MRC, MA

Human Development Institute at
Kentucky



How We Got Here



ADVOCACY AND DECISION MAKING

Moderator:

Holly Riddle, JD, Chair, AAIDD Legal Process & Advocacy Division

National Resource Center for Supported Decision-Making: Preliminary Developments and Outcomes

Tina Campanella, MA, Quality Trust for Individuals with Disabilities

Jonathan Martinis, JD, Quality Trust for Individuals with Disabilities

Michael Wehmeyer, PhD, FAIDD, University of Kansas

Voice & Advocacy—Complexities of the Guardian's Role

Alya Reeve, MD, University of New Mexico

Eula Michaels, University of New Mexico

System Change to Promote Rights: National Core Indicators Data and a Supported Decision Making Initiative

Elizabeth Bell, MSW, Human Services Research Institute

Deborah A. Dorfman, JD, Center for Public Representation

Paige Emerson, SDM Pilot Advisory Council

Amanda Benoit, SDM Participant

Maggy Walto, MS, Nonotuck Resource Associates

Room: Breathitt (Suite Tower-2nd Floor)



Okay, now
what?

- Took the idea to Kentucky Protection & Advocacy.
- Contacted Jonathan Martinis/National Resource Center for Supported Decision-Making.
- Need \$...

My Choice Kentucky is Born!

October, 2015



Partners:

- Kentucky Protection & Advocacy
- National Resource Center

Goal- Spread the work across Kentucky about supported decision-making.

Attended SDM Symposium the same month- got really overwhelmed



Justice for Susie! July 24, 2017

HDI SEMINAR SERIES

phone 859-257-3360 | email walt.bower@uky.edu

 Human Development
Institute

Disability Law and Policy: Emerging Trends and Future Practice

Friday, September 22, 2017 1:00 – 3:00pm EST

Gatton Business and Economics Building, Room 311
550 South Limestone, University of Kentucky, Lexington KY

Presenter: Peter Blanck, Ph.D., J.D.

prior individuals in the history of the University. He also is Chairman of the Burton Blatt Institute.

As people, we strive to have the authority to self-govern our lives and navigate the path toward our futures. For people with disabilities, this isn't always the case. There are many laws that shape the public discourse on the civil rights of people who have disabilities. This dynamic seminar will examine modern disability law and policy and the advancement of the fundamental rights people with disabilities have to fully participate in society. The seminar will also explore the disability rights movement and discuss current trends like Supported Decision Making, a process that empowers people to make life decisions with the help of friends, family members and trusted professionals.

Learning Objectives:

1. Learners will become familiar with the body of study on the efficacy of SDM as a fundamental human right.
2. Learners will have a deeper understanding of disability law and policy to advocate for the fundamental rights of people with disabilities to have full and equal participation in society.

CEU's are pending in Rehabilitation Counseling in conjunction with the Kentucky Office of Vocational Rehabilitation. CEU's are pending in Effective Instructional Leadership.

Registration: Electronic registration will open August 23, 2017. Visit HDI.Seminar.Registration to register for the seminar. For help registering, contact walt.bower@uky.edu



UK CENTER FOR EQUALITY
AND SOCIAL JUSTICE



You Don't Have To Do It Alone: Collaboration at Kentucky's UCEDD

Laura Butler¹, Jonathan Martinis², Camille Collins-Dean³, Bev Harp¹, Amy Cooper-Puckett⁴

¹ University of Kentucky ² Syracuse University, ³ Kentucky Protection & Advocacy, ⁴ Kentucky Office of Autism



My Choice Kentucky

My Choice Kentucky is partnership between the Human Development Institute at the University of Kentucky (HDI), the Burton Blatt Institute at Syracuse University (BBI), and Kentucky Protection & Advocacy (P&A). The primary goal of this project to identify and implement supported decision-making (SDM) based supports and services for project participants, helping them retain or regain their right to direct their own lives, free from overboard or undue guardianship. Participants use SDM to work with their natural supports and their service providers to identify specific goals and objectives designed to help them maximize, retain, or regain their right to direct their own lives, free from guardianship. They will then develop joint, collaborative and coordinated service plans identifying and implementing supports and services designed to help the person meet those goals and lead an independent, community-included life.

In this partnership, BBI provides technical and legal support to the project staff. BBI brings expertise in SDM and practical legal experience representing people in rights restoration cases using SDM. HDI is funding the project and coordinating the team members, in addition to evaluating the pre/post data. P&A is recruiting the project participants and providing direct support to the team. Thus far, two people involved in the project have had their rights restored. Each had a public guardian prior to rights restoration. Three other people have been enrolled in the project and are in the process of forming their SDM teams. More participants will be enrolled in the coming months.

Success!



Susie posing with her dream board and her attorney and a member of team after successfully petitioning to have her rights restored. Read Susie's stories in the Summer/Fall issue of Exceptional Family Ky magazine.

INTRODUCTION

Collaboration and self-determination are core values of University of Kentucky's Human Development Institute (HDI). Here we have highlighted two projects on which HDI is currently collaborating with other agencies, in and out of Kentucky. My Choice Kentucky and Innovative Supports for Autistic Workers rely on significant input from self-advocates in promoting self-determination. Each of these projects is, at its heart, an effort to provide a path for people to live and work in the manner they chose. Both ISAW and My Choice Kentucky work to ensure that self-advocates are able to make their own life choices and have the support in place to bring those choices to fruition.

COLLABORATORS



Kentucky Office of Autism,
DBHDD

Innovative Supports for Autistic Workers

Innovative Supports for Autistic Workers (ISAW) is a collaboration between Kentucky's Office of Vocational Rehabilitation (OVR), the Kentucky Office of Autism, and UK's Human Development Institute (HDI). Using a "train the trainer" approach, ISAW provides Business Service Teams across the state with information on autism and employment.

A unique feature of the project is its development and delivery by autistic self-advocates. In addition to the full time autistic staff person, ISAW partners with a team of six self-advocate consultants who provide valuable insight via lived experiences. From these self-advocates, Business Service Teams are able to learn, for example, that the accommodations autistic workers most need are rarely expensive or difficult to provide. Through their engagement in the project, autistic job seekers may gain greater access to hiring managers and have their needs better understood and accommodated.

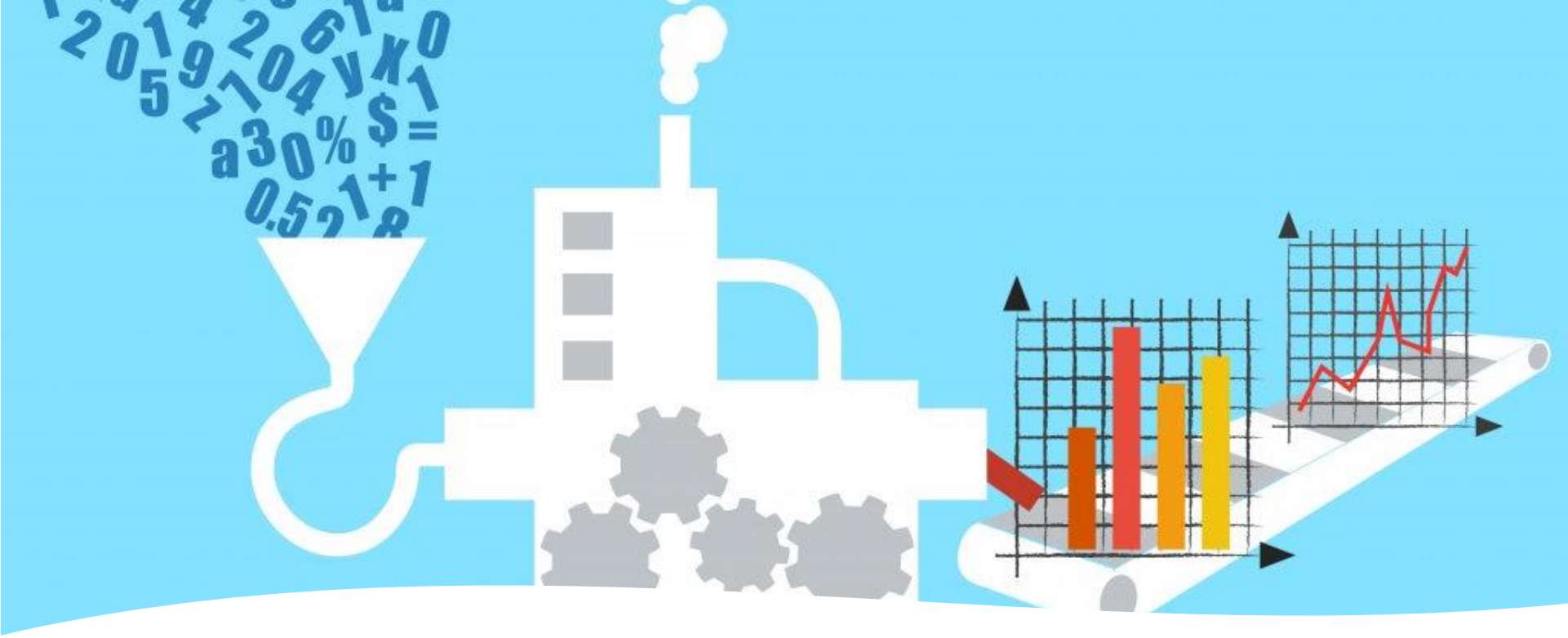
ISAW training comprises both online training modules and in-person workshops. Modules describe key characteristics of autism and how these impact workplace experiences.

Constructive approaches to common problems in interviewing and supervision are suggested. In-person trainings include real life scenarios and opportunities for discussion and further collaboration.

In October of 2017, ISAW worked with OVR, Kentucky Autism Training Center, and the Kentucky Office of Autism to produce Autism: Transitions Across the Lifespan, a Summit for Self-Advocates, Parents, and Professionals in Northern Kentucky. Having grown out of a series of "parent summits," this was the first such event in the state to include self-advocates at every stage of the planning process, and to provide a forum for all of these groups to share their knowledge and experience on an equal playing field.



Spreading the word with some help from our friends!



Guardianship Data

- How many?
- Who?
- Where?

Always be on the lookout for new opportunities

WITH Foundation

Work for Inclusive and Transformative Health Foundation
(formerly Special Hope Foundation)



Request for proposals targeted toward supported decision-making.

My Choice Kentucky: Making Decisions in Healthcare/Dental Care

Partnered with the University of
Louisville School of Medicine,
then University of Kentucky
College of Dentistry

Created teams that included:

- Young adults with intellectual & developmental disabilities
- Subject matter experts
- Family members



Lessons Learned



- Things will not go as planned
- You will hear every “what-if” scenario
- Everyone makes mistakes
- Learn from others.





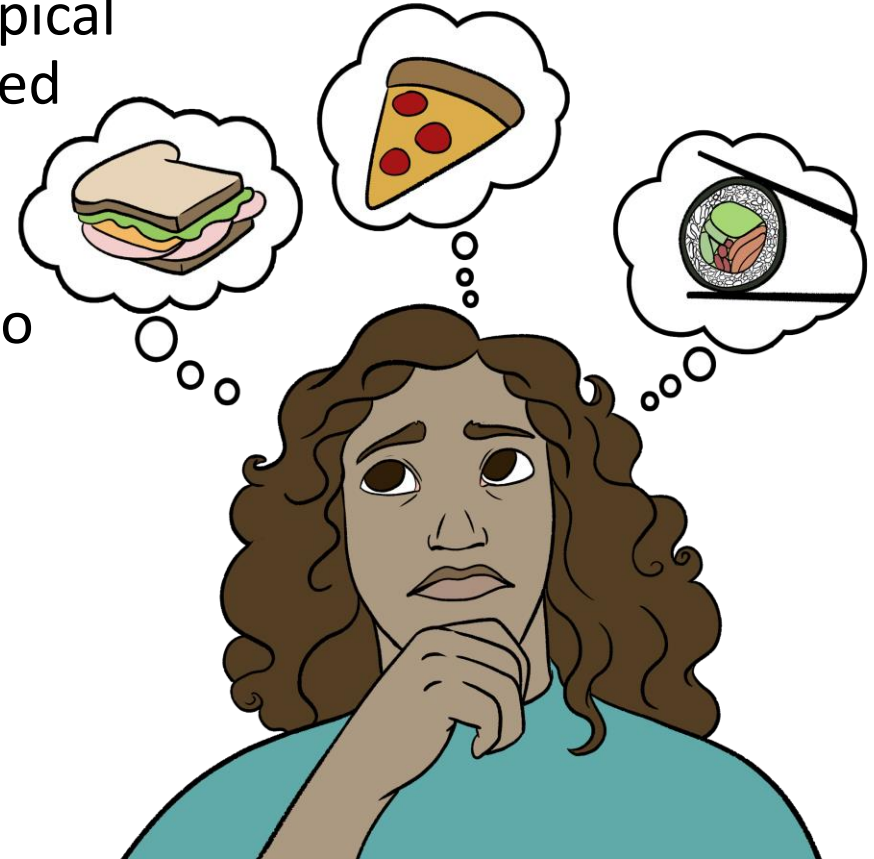
Partners, Collaborators, and Funders

- Kentucky Protection & Advocacy
- National Resource Center on Supported Decision-Making
- Burton Blatt Institute
- Southeast ADA Center
- University of Louisville School of Medicine
- University of Kentucky College of Dentistry
- WITH Foundation
- Commonwealth Council on Developmental Disabilities
- KY SPIN
- YES! Self-Advocacy Group
- Child Neurology Foundation

The NEW My Choice Kentucky

Continue and expand project efforts.

- Find ways for people without typical natural supports to use supported decision-making
- Increase groups educated
- Create materials for education to large and small groups
 - Flyers
 - Videos
 - Implementation guides



Contact

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Like us on Facebook! My Choice Kentucky



Green Mountain Self-Advocates

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