SUPPORTED DECISION-MAKING IN ACTION

Morgan K. Whitlatch

Legal Director,
Quality Trust
Project Director,
National
Resource
Center for
Supported
Decision-Making

SOME BACKGROUND

- Quality Trust Decision-Making in DC
- "Justice for Jenny" Case
- ■Invitational Symposium 2013
- U.S. Department of Health and Human Services Administration for Community Living – RFP on Supported Decision-Making
- International Backdrop: Convention on Rights of Persons with Disabilities

SUPPORTED DECISION-MAKING: INTERNATIONAL BACKDROP

Convention on the Rights of Persons with Disabilities

http://www.un.org/disabilities/convention/convention nfull.shtml

Article 12 – Sets out that people with disabilities:

- "have the right to recognition everywhere as persons before the law."
- "enjoy legal capacity on an equal basis with others in all aspects of life"

CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES, ARTICLE 12

State parties shall:

- "take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity."
- "ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards that prevent abuse in accordance with international human rights law."

GUARDIANSHIP IN THE U.S.

Estimated number of adults under guardianship has **tripled** since 1995 (Reynolds, 2002; Schmidt, 1995; Uekert & Van Duizend, 2011).

Publicity of overuse/misuse of guardianship

- Columbus Dispatch's Unguarded Series (2014)
- New York Times' Story on Dino and Lillian (2015)

GUARDIANSHIP IN THE US

"Plenary" or "Full" Guardianship

- Gives the Guardian power to make ALL decisions for the person.
- Used in the vast majority of cases (Teaster, Wood, Lawrence, & Schmidt, 2007).
- Most commonly recommended course of action by professionals (Jameson, et al. 2015)

NATIONAL RESOURCE CENTER ON SUPPORTED DECISION MAKING

- Funded in 2014 by the Administration on Community Living
- Focused on Research, Training and Information Sharing about Supported Decision Making (SDM)
- Addressing the issues of people who are aging and people with disabilities
- Linking development efforts throughout the country
- www.SupportedDecisionMaking.org

GOALS FOR THE PROJECT

- Build national consensus on SDM
- Change attitudes regarding decision making and capacity
- Identify and develop principles and tools for interdisciplinary support across the lifespan for with people of varying abilities, challenges and life situations.
- Increase collaboration and information sharing for implementing of SDM principles.
- Bring together training and technical assistance network promoting practices consistent with SDM

SUPPORTED DECISION-MAKING: WHAT?

- Supports and services that help an adult with a disability make his or her own decisions, by using friends, family members, professionals, and other people he or she trusts to:
 - Help understand the issues and choices;
 - Ask questions;
 - Receive explanations in language he or she understands; and
 - Communicate his or her own decisions to others.

(See, e.g., Blanck & Martinis 2015; Dinerstein 2012; Salzman 2011)

SUPPORTED DECISION-MAKING: WHAT?

- There is no "one size fits all" method of Supported Decision-Making
- It is a paradigm, not a process or program
 - It means working with the person to identify where help is needed and finding a way to provide any help that's needed.
 - Solutions are different for each person.
 - The key question is "what will it take?"
 - The possibilities are endless

IN THE WORDS OF ACL...

Supported Decision-Making "is not a program. Rather, it is a process of working with the person to identify where help is needed and devising an approach for providing that help."

"The solutions also are different for each person. Some people need one-on-one support and discussion about the issue at hand. For others, a team approach works best. Some people may benefit from situations being explained pictorially. With Supported decision-making the possibilities are endless."

Administration for Community Living, "Preserving the Right to Self-determination: Supported Decision-Making"

COMMON CONSIDERATIONS IN SDM

- All forms of SDM recognize:
 - The person's autonomy, presumption of capacity, and right to make decisions on an equal basis with others;
 - That a person can take part in a decision-making process that does not remove his or her decisionmaking rights; and
 - People will often needs assistance in decisionmaking through such means as interpreter assistance, facilitated communication, assistive technologies, and plain language.

(Dinerstein, 2012)

SUPPORTED DECISION-MAKING: WHY?

Self-Determination

Life control — People's ability and opportunity to be "causal agents . . . Actors in their lives instead of being acted upon"

(Wehmeyer, Palmer, Agran, Mithaug, & Martin, 2000, p. 440)

People with greater self-determination are:

- More independent
- More integrated into their communities
- Healthier
- Better able to recognize and resist abuse

(Powers et al., 2012; Shogren, Wehmeyer, Palmer, Rifenbark, & Little 2014; Wehmeyer & Shwartz, 1997 & 1998; Wehmeyer & Palmer, 2003; Khemka, Hickson & Reynolds 2005; Wehmeyer, Kelchner, & Reynolds 1996)

SUPPORTED DECISION-MAKING: WHY?

■ When denied self-determination, people can:

- "[F]eel helpless, hopeless, and self-critical" (Deci, 1975, p. 208).
- Experience "low self-esteem, passivity, and feelings of inadequacy and incompetency," decreasing their ability to function (Winick, 1995, p. 21).

Decreased Life Outcomes

Overbroad or undue guardianship can cause a "significant negative impact on . . . physical and mental health, longevity, ability to function, and reports of subjective well-being" (Wright, 2010, p. 354)

SUPPORTED DECISION-MAKING: WHY? RYAN'S STORY



"Ryan is a whole person. We want him to be whole. The decision process is part of being whole . . . If I try to force Ryan to do something, I am destroying his selfness and being whole. He is a whole person and he is making decisions and I encourage him."

For more on Ryan's story, visit http://www.supporteddecisionmaking.org/ impact-stories/ryan-king

Herbert King

- Ohio Rev. Code Ann. 2111.02(A): "If found necessary," a probate court shall appoint a guardian of the person, the estate, or both of an "incompetent" person.
- Ohio Rev. Code Ann. 2111.02(C) Prior to the appointment of a guardian or limited guardian . . . the court shall conduct a hearing on the matter of the appointment . . . Evidence of a less restrictive alternative to guardianship may be introduced, and when introduced, shall be considered by the court."

Ohio Rev. Stat. Ann. 5123.043

(A) Unless a guardian has been appointed for the individual, when a decision regarding receipt of a service or participation in a program provided for or funded under this chapter [County Boards of DDs] or Chapter 5123 [DDS] or 5124 [ICF/IDD Services] of the Revised Code by an individual with [a] developmental disability must be made, the individual shall be permitted to make the decisions. The individual may obtain support and guidance from an adult family member or other person, but doing so does not affect the right of the individual to make the decision.

- Ohio Rev. Stat. Ann. 5123.043
- (D) Individuals with developmental disabilities, including those that have been adjudicated incompetent pursuant to Chapter 2111[Guardianships, Conservatorships] of the Revised Code, have the right to participate in decisions that affect their lives and to have their needs, desires, and preferences considered. An adult or guardian who makes a decision pursuant to division (B) or (C) of this section shall make a decision that is in the best interests of the individuals on whose behalf the decision is made and that is consistent with the needs, desires, and preferences of the individual.

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SUPPORTED DECISION-MAKING: How?

- Effective Communication
- Supported Decision-Making Guide
 - http://supporteddecisionmaking.org/legalresource/supported-decision-making-brainstormingguide
- Informal of Formal Supports
- Peer Support
- Practical Experiences
- Role Play and Practice
- Life Coaching
- Mediation

SUPPORTED DECISION-MAKING: TOOLS

- Written Documents
 - Release of Information forms "HIPAA" or "FERPA"
 - Other Written Plans
- Written Agreements
 - Statutory Forms in TX and DE
 - Model Forms
 - http://supporteddecisionmaking.org/node/390

SUPPORTED DECISION-MAKING: OPPORTUNITIES ABOUND!

- Person Centered Planning in the Medicaid World
- Student Led IEP in Special Education
- Informed Consent in Medical Care
- Informed Choice in Vocational Rehabilitation
- Within the Guardian/Person Relationship

For Archived Webinars on the above, visit: http://www.supporteddecisionmaking.org/ education



In a recent survey, 10% of people under guardianship or who sought guardianship for someone identified a medical professional as the person who first recommended it.

(Jameson, et al 2015)

KEY CONCEPT: "INFORMED CONSENT"

Like "Capacity" is to guardianship, it is the lynchpin of self-determination in medical care

Three Key Parts:

- Information to the person
- •Understanding by the person
- Choice by the person

SDM IN HEALTH CARE

Assistance can be provided to help individual make medical decisions:

"Explain that to me in English"

- Doctor must reasonably accommodate the person's disability when obtaining his or her informed consent
- Role of "HIPAA" Release Forms
- Remember that the ability to make decisions is a continuum – ex.: flu shot versus open heart surgery.

ENABLE INFORMED CONSENT IN WAYS THAT ARE:

- Flexible
- Immediate
- Improve Dr-Patient communication and collaboration
- Increase the role of family, friends, and people close to the patient

"PERSON CENTERED PLANNING" IN MEDICAID WAIVERS

REQUIRED in Medicaid HCBS Waiver programs - Final Rules CMS 2249-F and CMS 2296-F

Services MUST:

- Be Driven by the person
- Include people chosen by the person
- Occur at times/locations convenient to the person

WHAT IS PERSON CENTERED PLANNING?

Person Centered Plan MUST:

- Address "health and long-term services and support needs in a manner that reflects individual preferences and goals."
- Result "in a person-centered plan with individually identified goals and preferences, including those related community participation, employment, income and savings, health care and wellness, education and others."

www.medicaid.gov/medicaid-chip-programinformation/by-topics/long-term-services-andsupports/home-and-community-basedservices/downloads/1915c-fact-sheet.pdf

YOU CAN USE SUPPORTED DECISION MAKING

- To help the person understand all components of the plan
- To help the person prioritize what is important to him/her
- To help the person build a network of supporters for the plan and beyond
- To help the person communicate and implement his or her choices

SUPPORTED DECISION-MAKING: TRENDS IN U.S.

- Americans with Disabilities Act
- Case Law: SDM as an Alternative to Guardianship
- State Legislation
- Uniform Law Commission Drafting Committee & Uniform Guardianship and Protective Proceedings Act
- Policy & Professional Standards
- Pilot Projects
 - NRC-SDM State Initiatives
 - Texas
 - Massachusetts
 - New York

REMEMBER: U.S. AMERICANS WITH DISABILITIES ACT

- Link SDM to disability-related accommodation
 - •ADA provides civil rights protections for people with disabilities, including requiring "reasonable modifications to policies, practices, and procedures" to avoid discrimination.

SDM, ADA, & OLMSTEAD

- Link SDM to U.S. Supreme Court case, Olmstead v. L.C.
 - Greater Self-Determination = Community Integration.
 - People with IDD who do not have a guardian are more likely to have a paid job, live independently, have friends other than staff or family go and dates and socialize in the community, and practice the religion of their choice. (2013-2014 National Core Indicators).

SDM, ADA, & OLMSTEAD

- NY Olmstead Cabinet (10/2013): "Community integration includes the ability of people with disabilities to make their own choices to the maximum extent possible. Guardianship removes the legal decision-making authority of an individual with a disability and should, consistent with Olmstead, only be imposed if necessary and in the least restrictive manner" (pp. 27-28).
- D.C. Olmstead Plan (2016): "Develop and implement clear expectations, competency criteria, standards, policies and protocols for all LTS staff in the consistent use of person-centered approaches to service and planning, including using principles of supported decision-making (regardless of whether individuals have guardians or other substitute healthcare decision-makers."

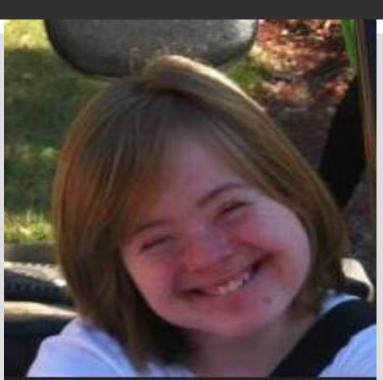
U.S. TRENDS: SDM in U.S. Case Law

- In re Peery, 727 A.2d 539 (Pa. 1999) Reversing guardianship order because the person "has in place a circle of support to assist her in making rational decisions concerning her personal finances and to meet essential requirements of health and safety"
- In re Dameris L., 956 N.Y.S.2d 848 (N.Y. Sur. Ct. 2012) —Terminating the guardianship of a person with an intellectual disability because she was "able to engage in supported decision making"

JUSTICE FOR JENNY

Margaret "Jenny" Hatch

- Twenty Nine years old
- High School graduate
- Lived and worked independently
- Volunteered in many political campaigns



THE SITUATION: FEBRUARY 2013

- Court Order putting Jenny in a "temporary guardianship"
- Living in a segregated group home
- No cell phone or computer, Facebook password changed
- Guardians controlled all access to her
- Working up to 5 days a week for 8 months
 - made less than \$1000

JENNY'S RIGHTS: IN ONE SENTENCE

Guardians Have the Power:

"[T]o make decisions regarding visitation of individuals with Respondent, Respondent's support, care, health, safety, habilitation, education, therapeutic treatment and, if not inconsistent with an order of commitment, residence."

ALL BECAUSE...

"She's going to need assistance to make decisions regarding her healthcare, her living arrangements and such like that, she will need someone to guide her and give her assistance."

WHAT THAT ALL ADDS UP TO

Jenny Needs Support:

- ■To Understand Legal Issues
- ■To Understand Medical Issues
- To Understand Monetary Issues
 - In her Day to Day Life

AND JUST LIKE YOU AND ME:

Decisions Jenny had made with Support

- Sign Power of Attorney
 - Consent to Surgery
- Medicaid Waiver Individual Service Plan
 - Application for Paratransit
 - Authorization to share medical records
 - Assignment of a Representative Payee

FINAL ORDER

- Ross v. Hatch, No. CWF120000426P-03 (Va. Cir. Ct. 2013) Appointing temporary limited guardians for only one year and charging them to "assist [the person] in making and implementing...'supported decision making'"
- Guardians to be who she wants
- She lives where she wants
- Guardianship for only 1 year <u>Expired</u> <u>August</u>, 2014
- Only over 2 things medical and safety

SDM IN U.S. CASE LAW

- Matter of D.D., 19 N.Y.S.3d 867 (N.Y. Sur. Ct. 2015) –
 Dismissing petition for appointment of a guardian in favor of supported decision-making
- Cory's Story, Berkshire County Probate Court; Pittsfield, MA (11/17/15) – Court found: "The SDM Agreement provides . . . A sensible, reasonable and workable arrangement to assist him to make his own decisions about all aspects of his life." http://supporteddecisions.org/cory/

SDM IN U.S. CASE LAW

- Matter of Hytham M. G., 2016 N.Y. Misc LEXIS 2722 (N.Y. Sur. Ct., Kings County, April 14, 2016) – Dismissing guardianship petition against a person with a developmental disability because of the availability of SDM.
- Matter of Michelle M., 2016 N.Y. Misc LEXIS 2719 (N.Y. Sur. Ct., Kings County July 22, 2016) – Dismissing guardianship petition against a person with an intellectual disability because of disability because of the availability of SDM.

TRENDS: LEGISLATION & STATUTES IN U.S.

- Statutory Supported Decision-Making Agreements
 - Tex. Estate Code Title 3, Chapter 1357 (eff. Sept. 2015)
 - Del. Senate Bill No. 230 (House passed July 1, 2016)
 - Pending: D.C. Bill 21-0385 (Intro. Sept. 2015)

LEGISLATION & STATUTES IN U.S.

- D.C. Supported Decision-Making & Education
 - D.C. Act 20-486, (eff. March 2015) "[S]tudent[s] who ha[ve] reached 18 years of age may receive support... to aid them in their decision-making"
 - Law reform preceded by D.C. Public Schools, Transfer of Rights Guidelines (Aug. 2013), recognizing SDM and advancing use of SDM Form.
 - See http://www.supporteddecisionmaking.org/impact-stories/supporting-decision-making-students-disabilities-dc.
 - Law reform resulted in District-wide Office of State Superintendent of Education Regulations recognizing supported decision-making (July 2016).
 - See http://osse.dc.gov/service/education-decision-making

LEGISLATION & STATUTES IN U.S.

- Supported Decision-Making & Health Care
 - Maryland S.B. 792 (enacted May 2015): Incorporated SDM in the medical context into proposed legislation concerning non-discrimination in access to organ transplantation.
 - Massachusetts H.B. 3271 (Intro. March 2015; HB 4332, Intro. May 2016): To do the same as above.

LEGISLATION & STATUTES IN U.S.

- Studies of Supported Decision-Making
 - Virginia H.J. Res. 190 Reg. Sess (2014): Ordered study of SDM, which recommended it be implemented in all service systems.
 - Maine H.B. 900 (enacted March 2016): Resolving that the Probate and Trust Law Advisory Commission will examine SDM and make recommendations about inclusion within Probate Code, with report due 1/15/17.

Uniform Law Commission

- Revisions to Uniform Guardianship and Protective Proceedings Act
 - Recent draft language would include a requirement that a court order for guardianship state "the court's finding . . . that the respondent's identified needs cannot be met by less restrictive means, including use of decisionmaking support..."
 - Revisions to the Act will have to be approved by the Uniform Law Commission

TRENDS IN POLICY & PRACTICE IN U.S.

- National Guardianship Association (May 2015) –
 Policy statement endorsing SDM, advising that it should be used before and within guardianship
- Center for Parent Information and Resources
 (Oct. 2015) Funded through U.S. Dept. of
 Education, CPIR released guidelines for parents on
 students reaching the age of majority, which
 included SDM principles

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TRENDS IN POLICY & POSITION STATEMENTS.

- Social Security Advisory Board (March 2016) Issue brief recognizing SDM as an alternative to SSA appointment of representative payee.
 - See http://ssab.gov/Portals/0/ OUR_WORK/REPORTS/ Rep_Payees_Call_to_Action_Brief_2016.pdf
- Joint AAIDD & Arc Position Statement (2016) "Autonomy, Decision-Making Supports, and Guardianship"
 - See http://aaidd.org/news-policy/policy/position-statements/autonomy-decision-making-supports-and-guardianship#.V8Xob6PD_nM
 - "The personal autonomy, liberty, freedom, and dignity of each individual with I/DD must be respected and supported. Legally, each individual adult . . . Is presumed competent to make decisions for himself or herself, and each individual with I/DD should receive the preparation, opportunities, and decision-making supports to develop as a decision-maker over the course of his or her life time."

TRENDS IN POLICY & POSITION STATEMENTS

- ABA PRACTICAL Tool (2016) Helps lawyers identify and implement decision-making options for persons with disabilities that are less restrictive than guardianship.
 - See http://www.americanbar.org/groups/law_aging/ resources/guardianship_law_practice/practical_tool.html
 - Steps
 - Presume guardianship is not needed.
 - Reason Clearly identify the reason for the concern
 - Ask if a triggering concern may be caused by temporary or revisable conditions
 - Community Determine if concerns can be addressed by connecting the person to family or community resources and making accommodations
 - Team Ask the person whether he or she already has developed a team to help make decisions
 - Identify abilities
 - Challenges Screen for and address any potential challenges presented by the identified supports and supporters.
 - Appoint legal supporter or surrogate consistent with person's values and preferences
 - Limit any necessary guardianship petition and order.

NRC-SDM STATE PROJECTS

- Indiana
- ■North Carolina
- Delaware
- Maine
- Wisconsin

DELAWARE STATE GRANTEE YOUR SUPPORT, MY DECISIONS!



OTHER NRC-SDM STATE GRANTEE PRODUCTS

- Maine's SDM Coalition
 - Including videos, guides, training initiatives, and sample SDM form
 - http://supportmydecision.org/tools
- First in Families of North Carolina
 - http://www.fifnc.org/programs/connections.html

TEXAS SDM PILOT – UNIVERSITY OF TEXAS AT AUSTIN

- "INCLUDE" Project of the Richard and Ginni Mithoff Pro Bono Program, in partnership with the William Wayne Justice Center for Public Interest Law.
- 2014-2015 pilot targeted parents and adult students with disabilities in special education transition programs for counseling about SDM and alternatives to guardianship
- This project resulted in 102 families receiving one-to-one counseling with law students under supervision.
- 10 families adopted SDM.
- The project continues.

TX VOLUNTEER SDM ADVOCATE PILOT

- Resulted from H.B. 1454, 81st Texas Legislature (2009)
- Focused on people with IDD and other cognitive difficulties who live in the community
- TX Council for Developmental Disabilities funded the pilot, which was run by the Arc of San Angelo, beginning in March 2011
- Pilot report issued in December 2012
 - Prevented two unnecessary guardianships and ended another.
 - Established one ongoing relationship between a volunteer and a person with a disability.

TX VOLUNTEER SDM ADVOCATE PILOT – LESSONS LEARNED

- Addressing concerns about volunteer liability took time.
- Early emphasis on medical POAs faced resistance from physicians and attorneys
- Targeted outreach was needed for volunteer recruitment.
- Extensive education process for volunteers was needed
- People at imminent risk of guardianship not well served by volunteer SDM in the short term.
- Recruitment of people with disabilities faced resistance from state-funded service providers.
- Change in community expectations needed.

TEXAS SDM LAW CLINIC PILOT — UNIVERSITY OF TEXAS AT AUSTIN

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MASSACHUSETTS SDM PILOT

- Partnership between Nonotuck Resource Associates, a shared living provider, and Center for Public Representation (CPR), a disability legal advocacy organization
- Included an active advisory council and planning conferences with judges, families, people with disabilities, as well as national and international advocates.
- Plan Assist approximately 10 individuals with IDD and their families in Western MA to design and implement SDM as an alternative to guardianship, with CPR providing legal representation
- ■2 year pilot and evaluation by HSRI (2014-2016).

MASSACHUSETTS SDM PILOT

- Currently 9 adults, 24 to 80 years old, with IDD and varying levels of support
- Currently 1 participant with a guardian who supports change to SDM; 1 participant who has been discharged from guardianship in favor of SDM
- ■SDM networks of 2 to 10 supporters: parents, siblings, grandparents, aunts, past & current providers

MASSACHUSETTS SDM PILOT

- Designed each person's SDM arrangement around individual needs
- Developed SDM Pilot Toolkit:
 - SDM Representation Agreements
 - Durable Powers of Attorney
 - Health Care Proxies
- www.SupportedDecisions.org

SUPPORTED DECISION MAKING EVALUATION

- Year 1 evaluation
 - Released in December 2015
 - Provides recommendations for establishing a SDM pilot, including partnerships, choosing participants, creating plain language SDM agreements, ensuring needed resources and training, and structuring safeguards
- Year 2 evaluation
 - Will focus on outcomes of people using SDM

New York Pilot Project

- 5-year (4/1/16 3/31/21) initiative funded by NY's Developmental Disabilities Planning Council
- Collaboration of Hunter College, the Council on Quality and Leadership, and Disability Rights New York
- Expected outcomes include:
 - Developing and evaluating SDM educational campaign
 - Identifying culturally and geographically diverse participants with IDD
 - Developing a specialized model for SDM mediation
 - Formalizing decision-making plans/agreements between people and support systems
 - Collecting relevant data on individual outcomes and process to inform potential changes to New York law
 - Identifying funding methodologies to ensure long-term sustainability of the SDM initiative.
- See http://ddpc.nv.gov/supported-decision-making-0

DEVELOPMENTS IN RESEARCH

- NRC-SDM Sponsored Studies
 - To determine best practices in SDM
 - To determine whether use of SDM is correlated with improved life outcomes.
- NRC-SDM Survey on Supported Decision-Making in Practice
 - http://www.supporteddecisionmaking.org/node/396
- National Council on Disability Developing a report that examines guardianship and alternatives in view of the goals of the Americans with Disabilities Act.

DEVELOPMENTS IN EDUCATION & OUTREACH

- In last 6 months, NRC-SDM presented at over 60 events across the country to thousands of people and provided technical assistance on SDM initiatives across the country.
- NRC-SDM Archived webinars on moving SDM from theory to practice in education and youth in transition; vocational rehabilitation; services, supports, and health care; finances; etc. (www.SupportedDecisionMaking.org)
- Listserv, "Supported Decision-Making Interactive!"

TO REACH THE SDM GOAL:

Every person should be part of every decision about his or her life.

- We all need help making decisions.
- People with disabilities may need more or different help, but should be supported to exercise their **Right to Make Choices** in their own lives.

JOIN THE CONVERSATION

National Resource Center for Supported Decision-Making: SupportedDecisionMaking.Org 202-448-1448

Morgan K. Whitlatch MWhitlatch@DCQualityTrust.Org 202-459-4004

ABOUT THIS PROJECT

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