



Family Caregiving Advisory Council Meeting

May 20 – 21, 2020

Day 2



Welcome and Roll Call

Greg Link, Director
Officer of Supportive and Caregiver Services
Administration for Community Living



Agenda

May 21, 2020

- 1:00 – 1:15 Welcome, Roll Call, Re-Cap Day 1**
- 1:15 – 2:00 Respite Care Presentation with Council Discussion**
- 2:00 – 2:45 Data and Research Presentation with Council Discussion**
- 2:45 – 3:45 Working Session: National Caregiving Strategy Driver Diagram**
- 3:45 – 4:00 Wrap-up, Next Steps, Adjourn**

Respite Care

Jill Kagan

Director

ARCH National Respite Network and Resource Center



Respite Presentation

for the RAISE Family Caregiving Advisory Council

Jill Kagan, MPH
Lifespan Respite Technical Assistance Center
ARCH National Respite Network and Resource Center
May 21, 2020





Family Caregiving is Lifespan!

Majority of family caregivers caring for an adult care for someone ages 18-75 (54%).

- 20% of family caregivers care for someone ages 65-74;
- 20% care for someone ages 50-64;
- 14% care for someone ages 18-49.

Nearly 14 million children have special health care needs.

Sources: Caregiving in the U.S. 2020. National Alliance for Caregiving and AARP Public Policy Institute; and US Health Resources and Services Administration, The 2017-18 National Survey of Children's Health.

Respite

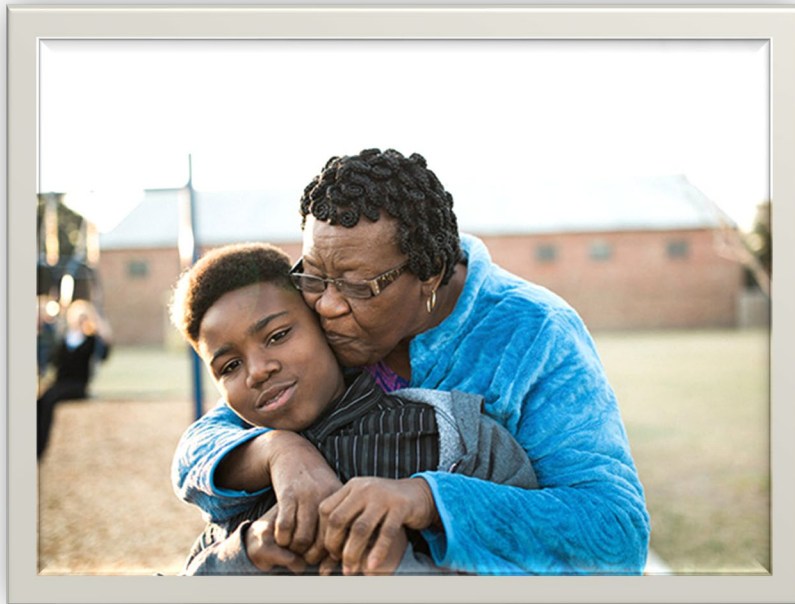


Benefits

Access

Barriers

Strategies



Respite is...

Planned or emergency care provided to a child or adult with special needs in order to provide temporary relief to family caregivers who are caring for that child or adult.

***Lifespan Respite Care Act definition
PL 109-442***

Types of Respite

- ❑ In-home respite
 - Consumer-directed
 - Home care agencies
 - Volunteer programs
- ❑ Out-of-home respite
 - Adult day care or child care centers
 - Facility-based (hospital, nursing homes, assisted living)
 - Community or faith-based
 - Provider's or other family's home





Respite may help --

- ❑ Improve family caregiver stress levels, which in turn, benefits caregiver physical and emotional health
- ❑ Improve overall family well-being, family relationships and stability
- ❑ Reduce social isolation
- ❑ Reduce hospital costs and avoid or delay more costly foster care, nursing home or other out-of-home placements
- ❑ Give care recipient a break, too!

Respite: Too Little, Too Late

- ❑ Just 14 percent of family caregivers report having used respite, though 38 percent feel it would be helpful (*2020 Caregiving in the US, NAC/AARP*).
- ❑ Of those who do, they often receive too little, too late.





Respite Barriers

- ❑ Limited government funding
- ❑ Cost
- ❑ Shortage of qualified providers
- ❑ Limited respite options, appropriate or preferred services
- ❑ Reluctance to use respite, ask for help, or self-identify as caregiver
- ❑ Access issues
 - Transportation
 - Multiple funding streams with confusing and restrictive eligibility
 - Lack of information

Paying for respite

- ❑ Medicaid Waivers
- ❑ Medicare Advantage Plans
- ❑ Family Caregiver Support Program
- ❑ Veterans Programs
- ❑ Lifespan Respite
- ❑ State Funded Respite Programs
- ❑ Disability or Aging organizations
- ❑ Self-pay or long-term care insurance

Proposed Strategies





Lifespan Respite ... a system of services

Lifespan Respite Definition:

Coordinated **SYSTEMS** of accessible, community-based respite services for all family caregivers regardless of age or special need.





Federal Lifespan Respite Care Program

U.S. Administration for Community Living administers competitive state grants for required uses of funds:

- ❑ Development or enhancement of State and local Lifespan Respite systems
- ❑ Planned or emergency respite for all ages
- ❑ Training and recruitment of providers/volunteers
- ❑ Provision of information to caregivers about respite services, and assistance in gaining access

Lifespan Respite Grant Activities

Statewide Respite
Registries

Connecting
families to respite

Volunteer and
Faith-based
Respite

Promoting
Informal Respite
Opportunities

Consumer-
directed Respite
Voucher Programs

Proposed Public Sector National Strategies for Expanding Respite Options

Consider	Consider Lifespan Respite approach as a state model
Make	Make permanent flexibilities currently approved for HCBS Medicaid Waivers granted to states under COVID-19
Ensure	Ensure respite is retained as a benefit in MLTSS
Add	Add respite as a benefit in traditional fee-for-service Medicare
Expand	Expand Medicare/Medicaid Hospice benefits to alternative settings

Proposed Public-Private Partnerships for Expanding Respite Options

Address	Address the Respite provider shortage through innovative recruitment and expanded training opportunities
Provide	Provide incentives to private insurance to include respite as a benefit
Support	Support business roundtables to encourage employer support for respite
Encourage	Encourage the expansion of an evidence-base for respite

For More Information



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ARCH National Respite Network
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Lifespan Respite Technical Assistance Center



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Respite Care Presentation with Council Discussion

1. What are the different types of respite care and their availability?
2. What are the barriers to respite care?
3. How can the availability of affordable respite care be increased for high risk populations?
4. Does a targeted outreach plan to identify faith-based and volunteer organizations make sense?
5. Is the creation of statewide respite registries doable?
6. Is a respite care benefit within Medicare feasible?
7. If respite care is expanded, what are the costs and where should the money come from? Are there any cost offsets?

Data and Research Presentation with Council Discussion

Dr. Scott R. Beach, Ph.D.

Director of the Survey Research Program
UCSUR/University of Pittsburgh



Large Family Caregiver Intervention Literature

- More than 50 systematic reviews/ meta-analysis since 2000
- Current AHRQ systematic review: 8409 references, 595 unique studies, 37 intervention categories – **Dementia caregivers only**
- Major finding was that – with a few exceptions (multi-component REACH II; collaborative care models) – evidence for the effectiveness of all interventions was inconclusive: evidence insufficient, uncertainty of evidence too high to draw conclusions
- Vast majority of Intervention studies focus on caregivers of older adults – and by far most of those are for dementia caregivers

Major Gaps in Caregiver Intervention Literature

- CGs of older adults with stroke, cancer, other diseases / chronic conditions (Some work on cancer, stroke cg interventions)
- CGs of those suffering from **Mental illness** (All ages)
- CGs of **younger care recipients**
 - parents of children and adolescents (0-17) with disabilities (e.g., autism; intellectual / developmental disabilities; Down syndrome)
 - CGs of younger / middle age adults with disabilities, serious mental illness, traumatic brain injury (veterans)
- CGs from **under-represented groups** (minorities; rural CGs; LGBT)

Major Gaps in Caregiver Intervention Literature

- Lack of data on **cost-benefit; cost-effectiveness** of caregiver interventions
 - economic costs of interventions relative to caregiver and societal outcomes
- Lack of data on **economic impacts** of caregiving
 - family caregiving as substitute for formal care, reduced health care costs and utilization
- **Intervention Implementation barriers** due to lack of strong evidence; funding; provider knowledge; contextual barriers

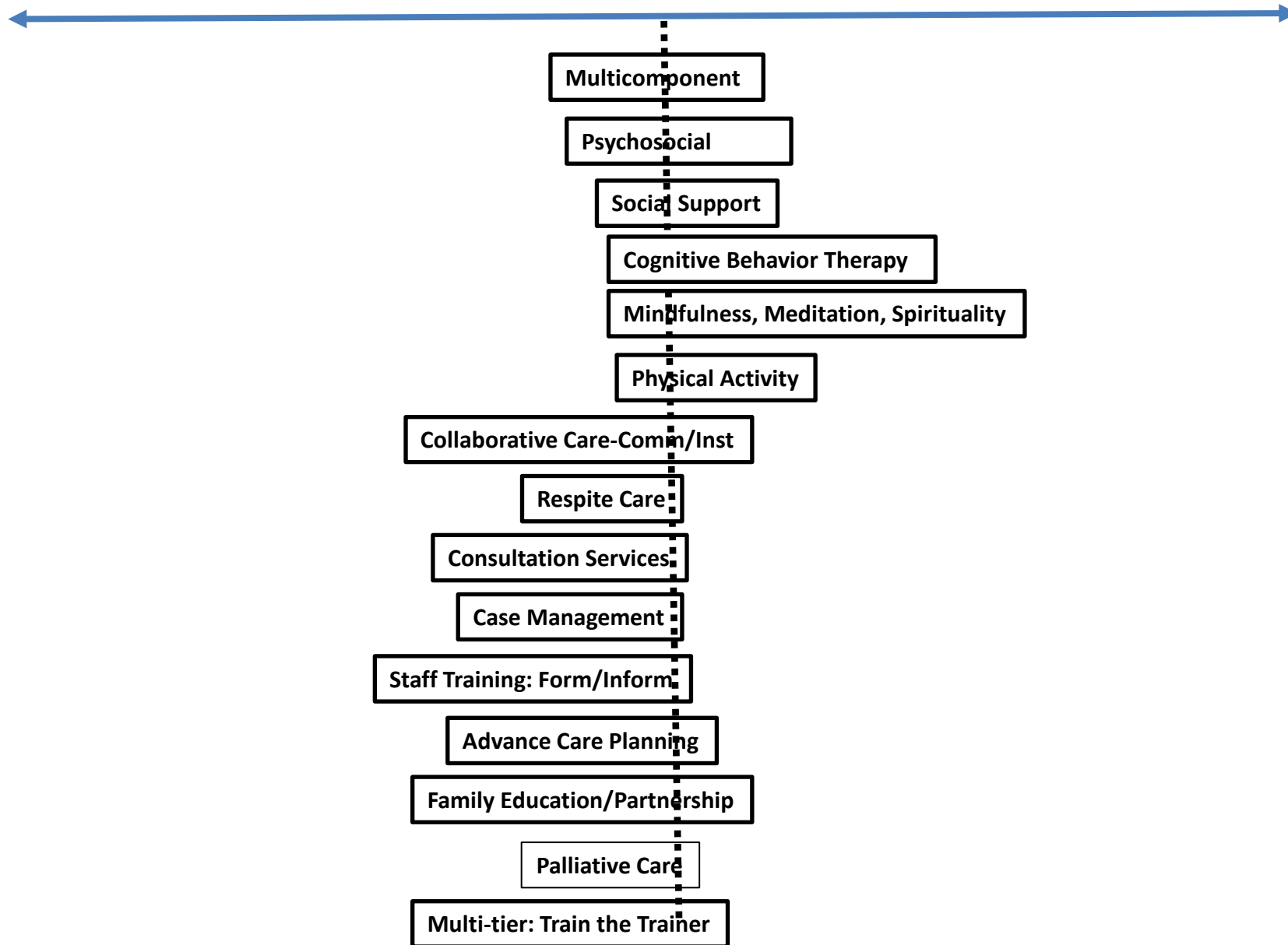
What we do know about effective interventions

Interventions should be multi-component and address:

- **Pragmatics** of providing care
 - Knowledge about illness, symptoms and progression, available support service
 - Skills to address needs of care recipient, assisting with functional disabilities, managing behaviors, accessing professional services
- Coping with **emotional toll** of caregiving
 - Living with, watching loved one suffer and decline, with little or no ability to mitigate conditions

Pragmatics Challenges

Emotional Toll



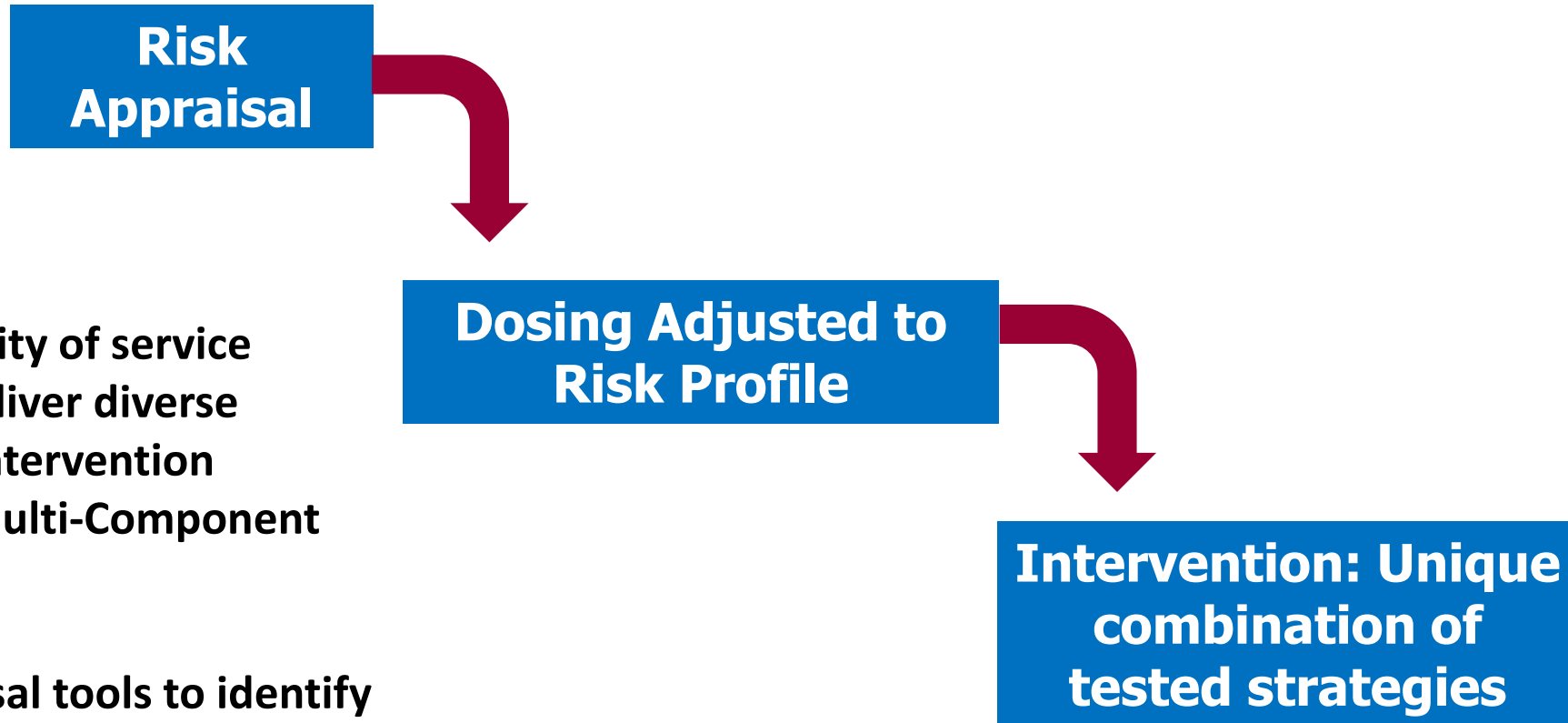
Moving Forward ...What we know..

- We understand and can measure CG needs and challenges
- We can identify high need/high risk CG/PWD dyads
- Risk/need profiles reflect CGs with multiple interrelated needs that are highly variable
 - Addressing single discrete needs with an intervention (e.g. respite, case management, social support) is not optimal
 - Scientific literature has evolved in this direction with poor results
- Logic dictates multi-component interventions adjusted for individual needs (e.g., REACH I to REACH II)

Moving Forward...

- Need nimble **highly tailored** intervention approaches
 - Broad array of options
 - Available options defined by existing intervention strategies
- Key is using **multiple strategies** and putting them together in ways that **address unique needs**
- Implementation research (adapting evidence-based intervention approaches to address the unique needs of caregivers in complex settings) could be an efficient and impactful approach to advancing the science of CG interventions.

Pragmatic Intervention Implementation Strategy



- Optimize capacity of service providers to deliver diverse components (intervention strategies) of multi-Component interventions
- Use risk appraisal tools to identify unique caregiver needs
- Tailor dosing to needs

Data and Research Presentation with Council Discussion

Joe Caldwell

Director, Community Living Policy Center

Lurie Institute for Disability Policy

Brandeis University

FAMILY CAREGIVING RESEARCH AND DATA

Joe Caldwell, PhD

RAISE FAMILY CAREGIVER COUNCIL MEETING
MAY 21, 2020

Need to improve family caregiving data

- **Very few sources of representative data currently exist**
 - Some sources do not include all caregivers across the lifespan
 - Limited state-level data
 - Often limited ability to identify sub-populations of caregivers
- **Most major national health and census surveys DO NOT include questions that identify family caregivers**

What currently exists?

- **Caregiving in the U.S.**
 - National Alliance for Caregiving and AARP
 - Conducted about every 5 years (new report this year)
- **National Study of Caregiving**
 - National Health and Aging Trends Study (NHATS)
 - Caregivers of Medicare beneficiaries over 65
- **Behavioral Risk Factor Surveillance System**
 - Optional state caregiving module
 - 2015-17 completed by 44 states, DC, and Puerto Rico



Some past and current efforts within Census Bureau

- **Survey of Income and Program Participation**
 - Used to have "topical modules," including one on informal caregiving
 - SIPP no longer has topical modules and caregiver questions have not been added
- **American Time Use Survey**
 - Includes questions on “eldercare” –condition related to aging
 - Access and Use of Leave module
- **American Community Survey**
 - Currently includes a question to determine grandparent caregivers

What might a core or uniform set include?

- **Basic information such as:**
 - Identify if an individual is a caregiver
 - Characteristics of care recipient
 - Level and duration of caregiving
 - Types of caregiving tasks performed
- **BRFSS and Caregiving in US provide good starting points**
- **Might not be feasible to get all questions added to surveys**
(for some surveys may only be able to get a single question)

What surveys to add questions to?

Depends on what you want to know...

- Do you want to know about caregiver health and wellbeing?
- Do you want to know about employment and economic well-being?
- How frequent do you want data reporting?
- What level of depth?
- Do you want data at the state level or national level?

Possible Opportunities

- **National Health Interview Survey**
 - Health insurance, healthcare utilization, chronic health conditions, employment.
 - Could question(s) be added?
- **Current Population Survey**
 - Employment, economic and social well-being.
 - Could a supplemental caregiver module be added every year or other year?
- **Behavioral Risk Factor Surveillance System**
 - Could question(s) be added to core or incentivize states to routinely do caregiver module?
- **American Community Survey**
 - Could question(s) be added to identify family caregivers, building on the existing question to identify grandparent caregivers?
- **American Time Use Survey**
 - Could “eldercare” question be modified? Or additional questions added to expand to all caregivers?

Improved Data on Caregiver Services and Supports

- Opportunities to also improve data on caregiver services and supports within Medicaid
 - Medicaid is the largest payer of long-term services and supports in the US
 - CMS is significantly improving Medicaid claims data through a new system called **Transformed Medicaid Statistical Information System (T-MSIS)**.
 - This includes new uniform elements for respite and caregiver training.
 - For the first time, we will be able to assess the extent to which states are providing these services and support and how many individuals are utilizing.
 - Once the system is fully operational, this could provide access to timely data on a regular basis to compare states and track progress.

Data and Research Presentation with Council Discussion

1. What type of family caregiver research and data are most lacking?
2. If better data is needed, is it possible to add family caregiver questions onto national surveys? If so, what are the key questions and national surveys?
3. Does research on cost-effective caregiver interventions and outcomes need to be amplified?
4. How can successful, evidence-based programs be scaled up and expanded to other types of family caregivers and disability types?

Working Session:

National Caregiving Strategy Driver Diagram

Greg Link, Director
Office of Supportive and Caregiver Services
Administration for Community Living



Wendy Fox-Grage, Project Director
RAISE Family Caregiving Resource and Dissemination Center
National Academy for State Health Policy (NASHP)



Working Session:

National Caregiving Strategy Driver Diagram

1. Given the four presentations we heard during Council meetings, for any of the goals/drivers, are there strategies, actions or programs that you'd like to see added to the Diagram (Columns C and D)?
2. Based on your review of the current iteration of the Driver Diagram, are you satisfied with the drivers currently listed under each goal?

Wrap Up & Next Steps

Greg Link, Director
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Thank You