Present: Arlene Poncelet, Tim Neyhart, Matt Cain, Carol Rockwell, Jen Red Bear, Molly Keegan, Bobbie Jo Leggett, Caitlin Borges, Erik Nelson, Shelly Pfaff, Kathi Herreid, Kay Ermish, Rachel Gangle, Michele Burgers, Brooke Pape Johnson, Colin Hutchison, Derek Biteler, Jennifer Gant, and Deb Petersen.

Absent: Wendy Parent-Johnson, Betsy Schuster, Ruth Thomas, Kathie Erdman-Becker, and Samantha Dewell.

Deb Petersen, Lifespan Respite Care Project Manager welcomed and thanked members for their participation on the Coalition and attending the meeting. Following introductions, Deb reviewed the contents of the binder provided to each member including a list of Coalition members, a compendium of other State Respite Coalitions Fact Sheets. Deb presented the ARCH National Respite Network and Resource Center Power Point entitled "Lifespan Respite Care 101". Post note: ARCH stands for Access to Respite Care and Help. Deb explained that members can join an ARCH listserv to receive emails on webinars and other information. The ARCH website is located at: www.archrespite.org. If members want information about ARCH webinars open to the public, to receive ARCH's publications, and to subscribe to ARCH Quick News Updates you can view past information and sign up to receive current news at: https://archrespite.org/subscribe-quick-news.

Deb reviewed key points from the Grant Narrative including barriers to using respite by caregivers, i.e., lack of providers and lack of trained providers. Discussion included that caregivers may be reluctant to use respite and the reasons why. Some caregivers view their role as being a family member and in that role it is 'what you do' so they don't self-identify respite as a need.

Discussion was held on member's experience in holding focus groups and the consensus was that when done correctly focus groups are beneficial. The group decided to postpone conducting focus groups until later in the grant period. Suggestions were made for a third party to lead and coordinate the focus groups. Kathi Herried spoke of her experience with "Maximizing Excellence" in Sioux Falls who was hired by the Alzheimer's Association. A variety of survey tools were used including Survey Monkey and written surveys with advertisements in the newspaper on how to obtain a survey. Colin Hutchison and Arlene Poncelet shared information about Community of Practice for Supporting Families (of individuals with developmental and intellectual disabilities) and that they had done some focus groups and obtained useful data. Discussion included the cost of a third party to conduct the focus groups would be more than what the grant budget could accommodate. Deb Petersen asked if we could tap into other support groups and discussion ensued on the various support groups in Sioux Falls and statewide.

Kathi Herreid, State Program Director at the Alzheimer's Association provided a presentation on Alzheimer's including data and information on caregiving for a person with Alzheimer's.

Derek Biteler, Program Specialist with the Division of Developmental Disabilities presented information on respite available through the Respite Care Program and the Family Support 360 Waiver. Deb Petersen and Jennifer Gant discussed the Division of Long Term Services and Supports Respite Care programs including the Caregiver Program, the Home and Community Based Services

Waiver and Under 60 Respite Care Program. Deb demonstrated the ADRC Resource Directory Learning Library and a folder titled "Caregiver". Links and resources could be improved to provide more information to Caregivers. The vendor that maintains the resource directory can build within it a respite provider registry. Deb and Jennifer shared that providers can update information in the directory at any time and once a year an email blast is sent to providers asking them to update their information. This would also be used to keep respite provider information current. Deb shared it would be her job to keep the registry updated with assistance from Jennifer and the vendor.

Erik Nelson, Associate State Director with AARP South Dakota presented on the SD AARP Caregiver Survey which is based on the information gathered from 1000 registered voters age 45 years and older who were contacted by telephone by a 3rd party (Precision Opinion) between May and June 2017.

Rachel Gangle Sioux Falls VA and Kay Ermish Black Hills VA presented on the Veteran's Administration's Caregiver Support Program and the availability of respite care to Veterans. They shared brochures, business cards and information on the VA website including mobile apps that are available to Veterans and general public located at: https://mobile.va.gov/appstore.

Deb Petersen distributed the grant work plan and reviewed progress on the work plan. A Department of Human Services State Workgroup held its first meeting on 11/01/2017 and began discussion on state respite programs, respite definitions, state respite webpages. The State Workgroup will work towards better aligning and streamlining information on state respite programs to increase consumer access.

Members shared not all people who need respite fully know what the term "respite" means. Discussion was held on how to better describe or define the word "respite". Suggestions included adding tag lines such as Arkansas has "Take the time" and Delaware has "When you need a break" Deb shared that Montana has a slogan about it being 'ok'. Also discussed was how to reach people who need respite. Deb explained the Department of Human Services is working with a marketing agency to rebrand the Aging and Disability Resource Center (ADRC) to Dakota At Home. Discussion was held on how respite could be included in the public awareness campaign. Molly Keegan shared information about the Wilder Foundation, St. Paul, Minnesota and that they have some award winning marketing tools we could possibly emulate for our purposes. She volunteered to share the information with the group.

Discussion on a provider registry and the role of background checks solicited varying opinions. Some members felt background checks only represented a point in time. Some expressed background checks were needed when providing a list of providers on a state sponsored website. A suggestion was made to have a list of providers with background checks completed and a list where caregivers need to do their own checks. All agreed education for caregivers was key on how to interview potential respite providers. Additional discussion items included: how to improve access to respite care and respite providers; are our respite programs being fully utilized; do people know what programs are available and whether they quality for a program or can pay privately; how to reach people so they know what is available; and what data do we not have that we think we need?

Shelly Pfaff requested a copy of what data elements are captured in the ADRC Call records. Jennifer Gant shared that we may need to alter Outcomes/Topics to help track Respite efforts. Post Note: Data Elements include: Call Type, Caller Name, Caller Type, Consumer Name, Caller was referred

by, Consumer Gender, Consumer Age Group, Consumer Disabilities, Consumer Low Income/Not Low Income, Call Outcomes, Topics Discussed. Deb shared she and Jennifer will participate in a Data Workgroup through ARCH with the 1st meeting on December 5th.

In a discussion on what the Coalition should be called, the group decided to keep the name simple: South Dakota Respite Coalition. Matt Cain and Carol Rockwell offered suggestions for the Coalition's mission statement. Following member discussion the grant's overall goal was suggested and decided as the Coalition's mission statement to read as follows: To improve overall access to respite care services for families and other caregivers.

Coalition members will reach out to others who may be valuable additions to the group. Deb asked for suggestions on any entities and people using respite care. Entities suggested include: Behavioral/Mental Health - NAMI, Palliative Care, Faith Community Nursing, Community of Practice, Indian Health Services and increased Native American representation. Members were asked to provide names to Deb by Dec. 15th. Discussion included how many members should be added but a consensus was not reached.

A webinar on Community of Practice Life Course Respite tools by Missouri was mentioned and Deb will provide the webinar information to members. Post Note: The ARCH National Respite Network and Resource Center and Missouri Family To Family will host this webinar on December 7th. Deb queried members on whether they found the (September) ARCH webinar on Emergency Respite informative. Deb asked members if they thought we could be ready to hold a Respite Summit in the coming year and that ARCH would assist in its planning. Member consensus is that we are not ready to hold a summit in this, our first year.

Forming subgroups was suggested and a list of subgroup topics was shared with members. Following discussion the following three subgroups were established by members:
- Public Awareness: Research Other States
- Members: Colin Hutchinson, Derek Biteler, Erik Nelson, Bobbi Jo Leggett, Rachel Gangle, Matt Cain, Deb Petersen, Jennifer Gant

- Surveys: Pre/Post Surveys – what we know and what we don't know
  Caregiver Satisfaction Surveys and research other states' collection methods
- Members: Bobbi Jo Leggett, Arlene Poncelet, Michelle Burgers, Kay Ermish, Deb Petersen, Jennifer Gant

- Respite Provider Registry: Research Other States: registry websites, if backgrounds
  checks are done and type, provider training, etc.
- Members: Brooke Pape Johnson, Shelly Pfaff, Tim Neyhart, Molly Keegan, Carol Rockwell, Jen Red Bear, Deb Petersen, Jennifer Gant

Member consensus was to hold an in person meeting in February in Pierre (suggestion on a Wednesday) and for those who are unable to travel to Pierre to participate via teleconference. The 3 subgroups will present information at the February meeting. An early May meeting in Sioux Falls was also discussed. Erik Nelson offered to hold the Sioux Falls meeting at AARP.