SDM/SDMA PROGRESS* IN THE LAST FRONTIER; SYSTEM-WIDE COLLABORATION AND FOCUSED LEADERSHIP IN ALASKA

*. . . AND WHAT WE ARE UP TO NEXT.

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GOVERNOR'S COUNCIL ON DISABILITIES & SPECIAL EDUCATION

ACRONYM DECODER

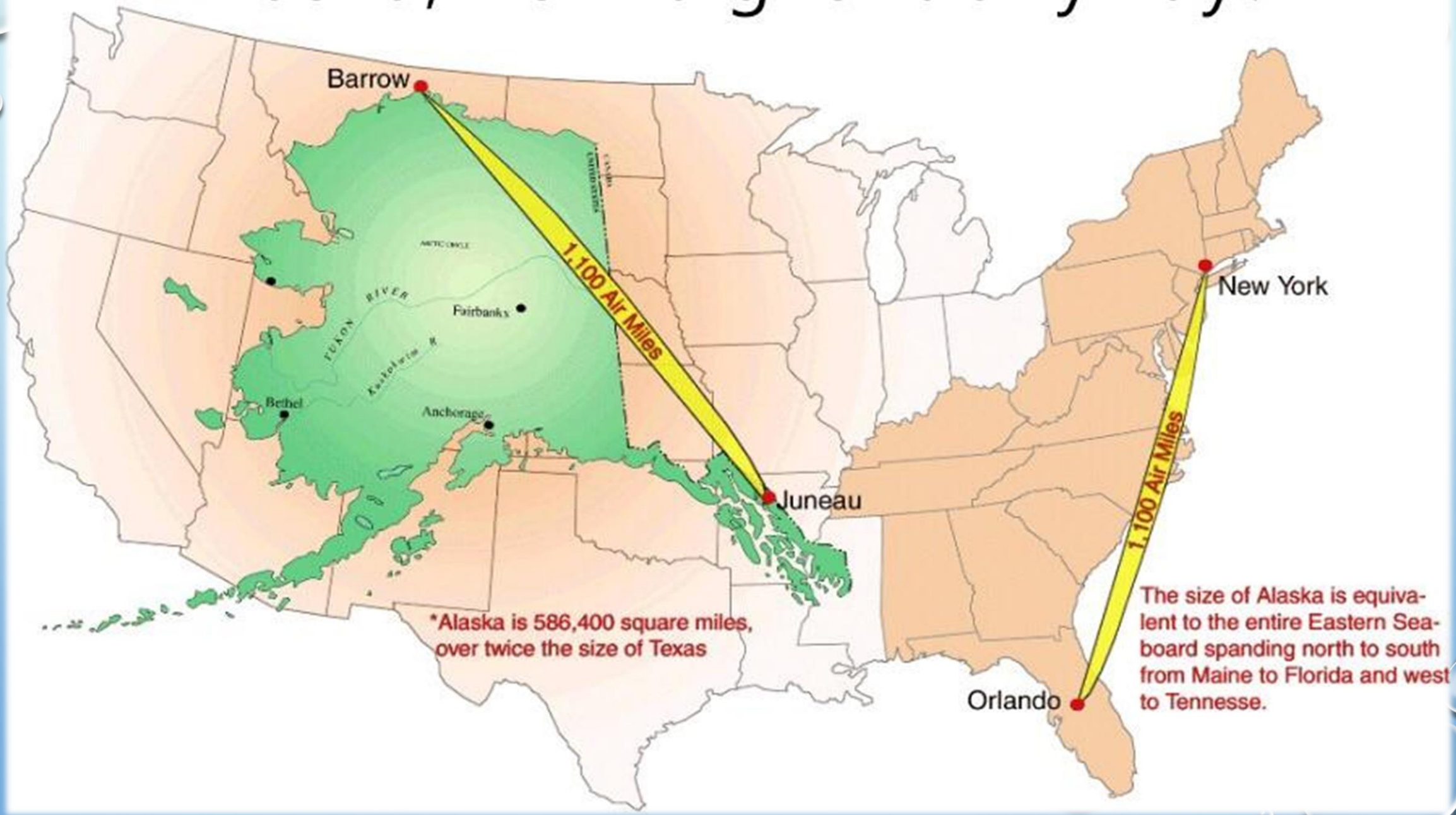
DD ACT NAME/NATIONAL UMBRELLA

- UCEDD = UNIVERSITY CENTER FOR EXCELLENCE IN DEVELOPMENTAL DISABILITIES
  - AUCD (NATIONAL)
- P&A = PROTECTION AND ADVOCACY AGENCY
  - NDRN (NATIONAL)
- DD COUNCIL = DEVELOPMENTAL DISABILITIES COUNCIL
  - NACDD (NATIONAL)

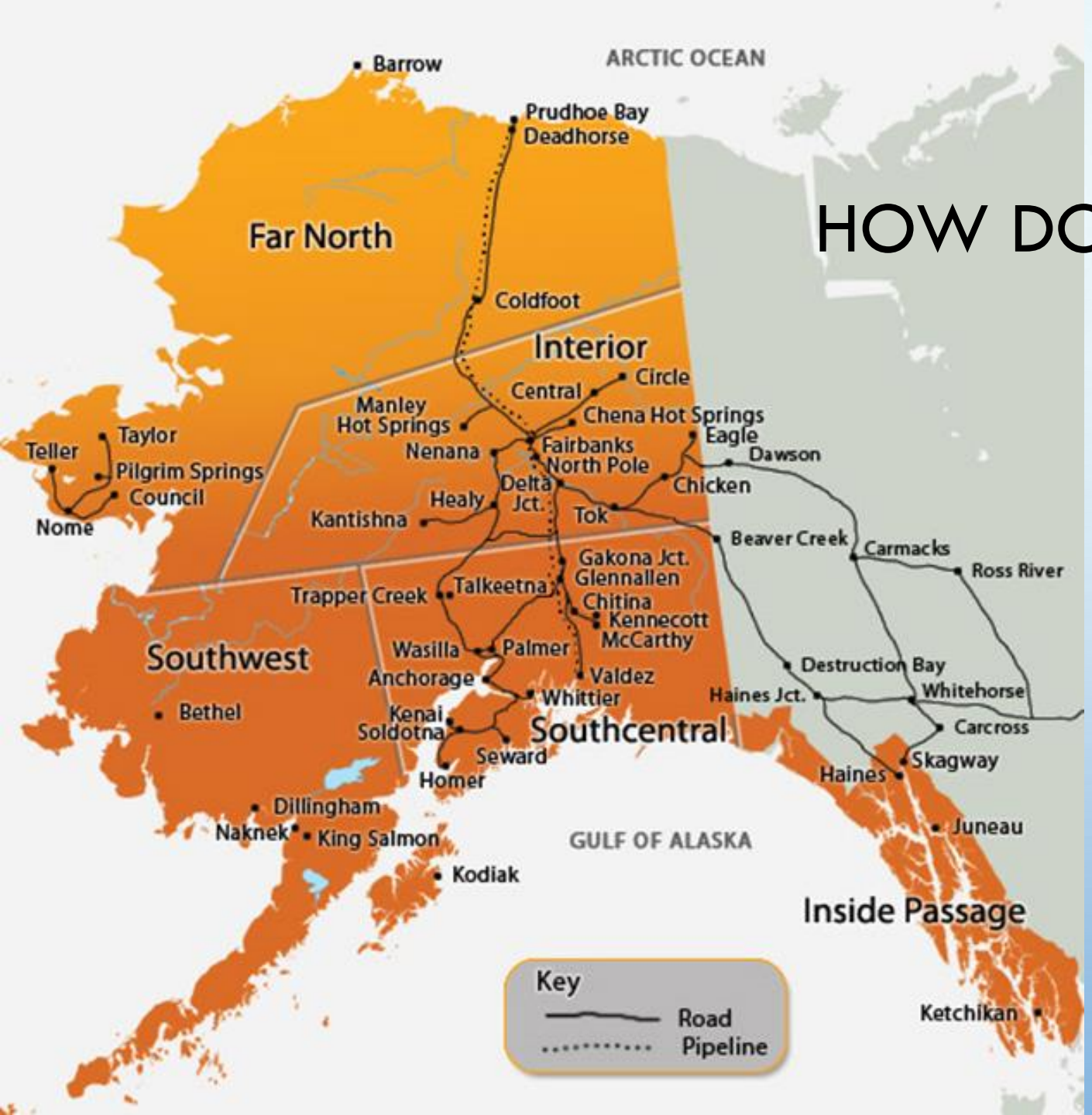
ALASKA NAME

- UAA CENTER FOR HUMAN DEVELOPMENT (CHD)
- DISABILITY LAW CENTER OF ALASKA (DLC)
- GOVERNOR'S COUNCIL ON DISABILITIES & SPECIAL EDUCATION (COUNCIL)

Alaska, how big is it anyway?

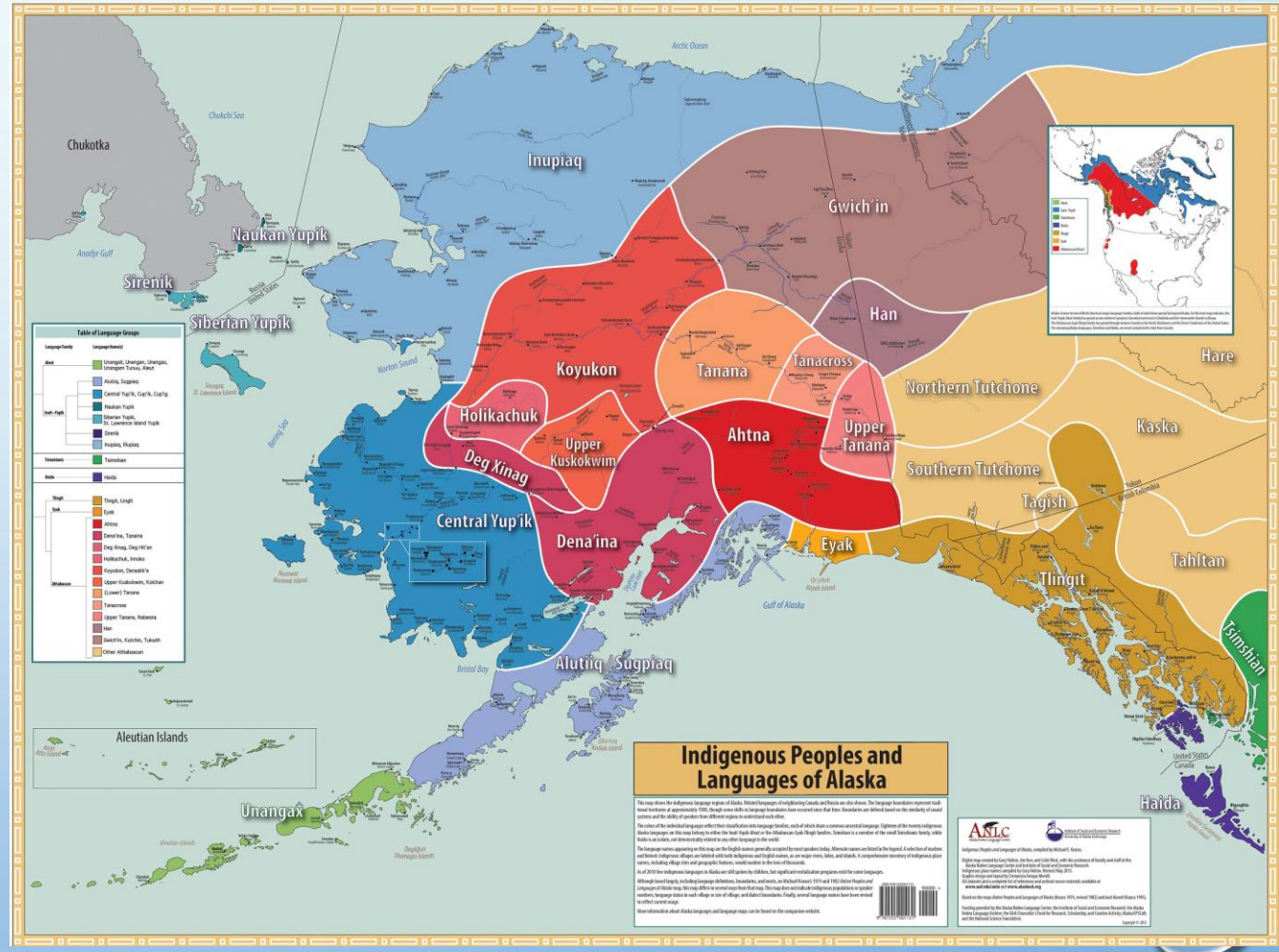


HOW DO WE GET AROUND?



SOME NUMBERS FOR PERSPECTIVE

- STATE POPULATION 739,795
- 14% ALASKA NATIVE/NATIVE AMERICAN
- ANCHORAGE: 295,365 PEOPLE
  - ANOTHER 100,000 SURROUNDING AREA
  - 103 LANGUAGES IN ANCHORAGE S.D.
- FAIRBANKS METRO: APPROX. 100,000 PEOPLE
- JUNEAU: 31,276 PEOPLE
- RURAL & REMOTE: ROUGHLY 300,000



Alaska is home to at least twenty distinct indigenous languages. More than just dialectal variants, these different languages reflect the diverse cultural heritage of Alaska's Native peoples.

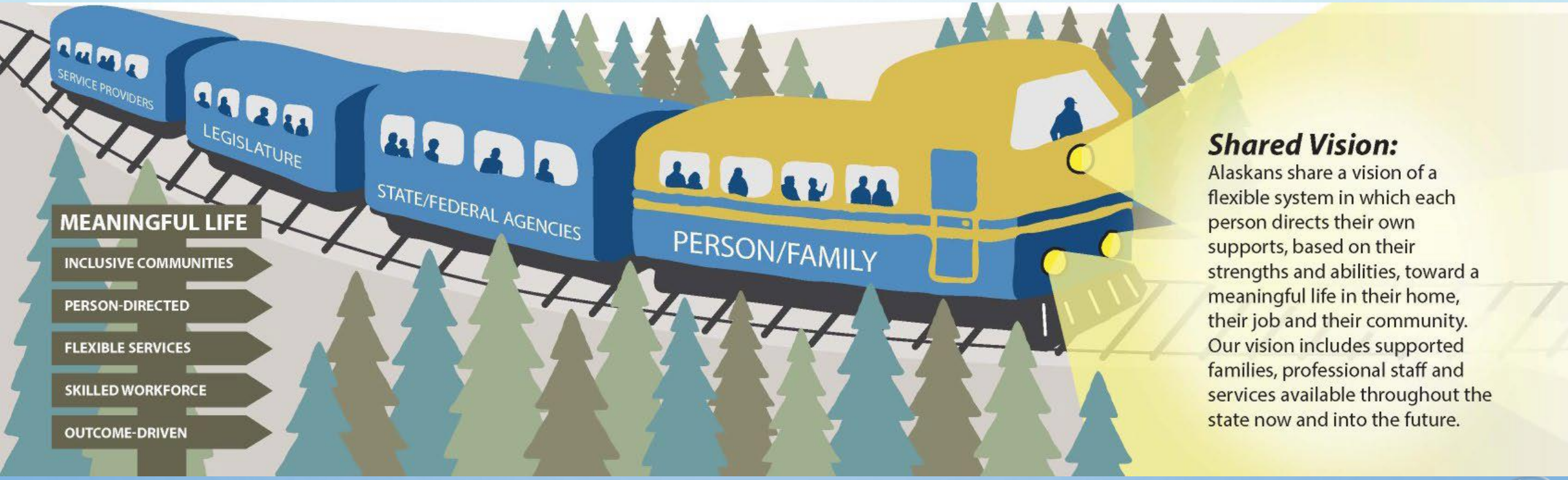
SOME OTHER RELEVANT INFORMATION

- SENIORS (87,304 IN 2018)
- ADULTS WITH DISABILITIES: WELL-ESTABLISHED URBAN NETWORK BETWEEN SERVICE PROVIDERS (WAIVERS), SCHOOLS & COLLEGES, EMPLOYMENT, COMMUNITY ENGAGEMENT; RURAL . . .
- MEDICAID: HOME AND COMMUNITY BASED SERVICES
- CONFLICT-FREE CARE COORDINATION
- NO RESIDENTIAL INSTITUTIONS (SOME ACUTE CARE, CRISIS OF SHORT TERM BEDS FOR MENTAL HEALTH)
- GUARDIANSHIP NUMBERS HIGH; PUBLIC GUARDIANS OVERWHELMED

HOW WE GOT HERE; QUICK TIMELINE ON SDM WORK

- AWARENESS AT DISABILITY LAW CENTER 2016; WINGS GRANT APPLICATION 2017
- COUNCIL EXEC. DIR. ATTENDED SDM TRAINING AT NACDD 2016
- LEAD MOVED FROM DLC TO DD COUNCIL APRIL 2017 (FIRST TRAINING 3/28/2017)
  - RIGHT PLACE AT THE RIGHT TIME
  - DD SHARED VISION
- FORMED SDMA WORK GROUP OUT OF COUNCIL'S DD COMMITTEE 2017
  - FIRST WINGS MEETING; COMMITTEE FOR ALTERNATIVES (QUARTERLY)
- MULTI-FRONT ACTIVITIES WORK PLAN 12/6/2018 (GREEN TABLE)

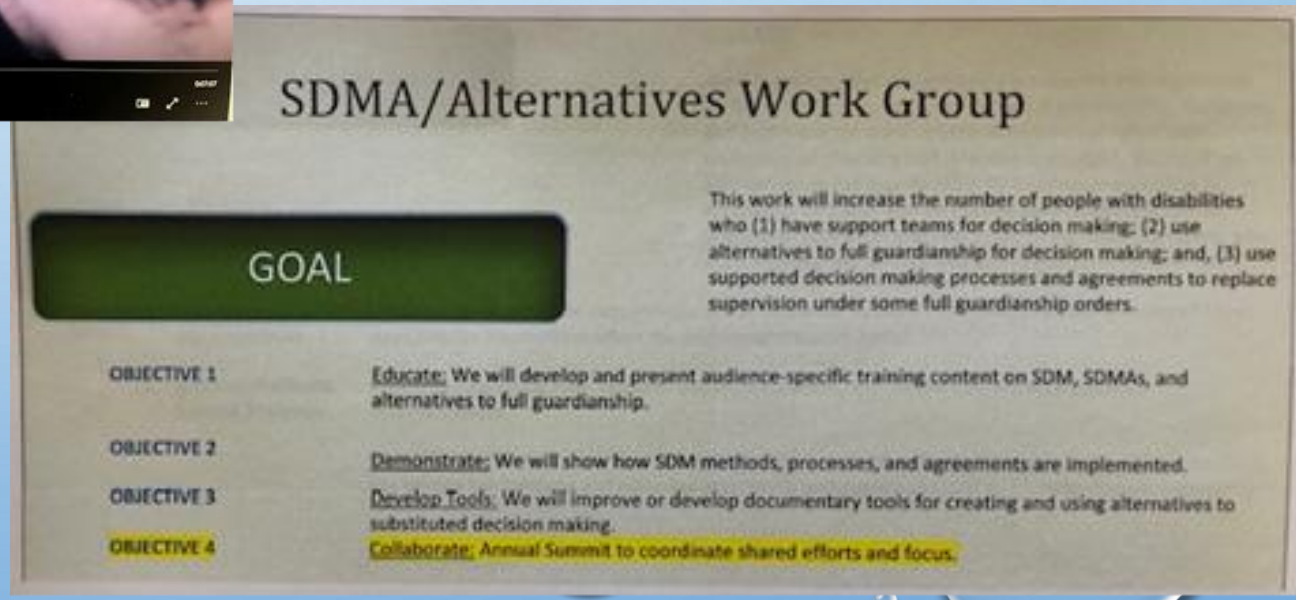
ROLE OF THE "DD SHARED VISION"



I LIVE THE LIFE I CHOOSE WITH THE SUPPORTS THAT I DIRECT.

WHAT WE HAVE DONE SO FAR

- WINGS (WORKING INTERDISCIPLINARY NETWORK GUARDIANSHIP STAKEHOLDERS)
- COUNCIL SDMA/ALTERNATIVES WORK GROUP
- TRAININGS
- LEGISLATION
- PILOT PROJECT
- ANNUAL SUMMIT
- WEBSITE
- VIDEOS AND WEBINARS
- *ALASKA MENTAL HEALTH TRUST AUTHORITY* FUNDING
- *WITH* FOUNDATION GRANT
- *AARP* GRANT(S?)
- *ACL LIVING WELL* GRANT



SDM/SDMA TRAININGS

- TURN TO PAGES 2, 3 ON THE GREEN WORK PLAN . . ..

- FOR EACH AUDIENCE:
  - SOMEONE TO GIVE INSIDER'S FEEDBACK ON MY UNDERSTANDINGS
  - RESEARCH WHAT OTHER PEOPLE HAVE SAID ABOUT THIS GROUP **RECENTLY**
  - FIND A "FRIENDLY" WITHIN THE ORGANIZATION, DISTRICT, SOCIAL GROUP
  - CAN WE RECORD THE SESSION FOR OUR WEBSITE?
  - CAN THEY INCLUDE IT ON THEIR WEBSITE?
  - CAN HOST INVITE OTHERS WHO ARE UNAFFILIATED?
  - CAN I COME BACK WHEN THERE ARE IMPORTANT DEVELOPMENTS?

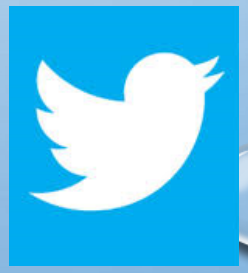
  - Do you have an organized outreach strategy? Ideas that seem to work well?

LEGISLATION (BEFORE FILING)

- LOOKED CAREFULLY AT EXISTING EXAMPLES; THOUGHT ABOUT EFFECT OF EACH CLAUSE (OR LACK OF DETAIL)
- WROTE A DRAFT BASED ON DELAWARE'S LAW, BUT MODIFIED
- SENT IT TO WINGS AND COUNCIL COMMITTEES TWICE
- WIDENED THE REVIEWING CIRCLE: COUNCIL, DHSS, AADD, WINGS, DLC, AARP (NATIONAL OFFICE)
- EVERY TRAINING DESCRIBED WHAT LAW SHOULD HAVE IN IT
- TEXAS'S EXPERIENCE WITH LEGISLATIVE PROCESS, IMPLEMENTATION, CLINICS, PUSHBACK, BAD OUTCOMES?, ETC.
- SPONSOR LEGISLATOR WAS A COUNCIL MEMBER

LEGISLATION (AFTER FILING)

- TESTIMONY: FORMER WARD, PARENT-GUARDIANS, AARP MEMBERS, U OF TEXAS LAW PROFESSOR
- SPOKE WITH THE COURT SYSTEM COUNSEL: NOT GOING TO OPPOSE; DITTO WITH PUBLIC GUARDIAN'S OFFICE
  - WINGS HELPED SMOOTH THOSE CONTACTS
- WORKED WITH THE LEGISLATIVE INFORMATION OFFICE ON DRAFTING
- LOBBYISTS FOR SERVICE PROVIDER AGENCY, AND PARENT-PEER ADVOCACY GROUP
- PUSHBACK FROM OUR OWN DIVISION WITHIN DHSS
- DELAY IN SENATE JUDICIARY (LINKING VOTE ON ANOTHER "DISABILITY BILL")
  - PARENT FACEBOOK PAGE
  - TEXT TREES
  - EMAIL LISTS
  - GOV.DELIVERY



ALASKA'S SDMA ACT

- ENACTED ON DECEMBER 26, 2018
- ALMOST UNANIMOUSLY PASSED IN LEGISLATURE
- SUPPORTED AND SIGNED BY THE GOVERNOR

- Have you run into opposition to SDMA legislation in your state?
- Why do you want/need a statute? What do you see it doing for people?
  - Focused on 3rd parties' obligations
  - "It's not an alternative to full guardianship, but a different kind of appropriate support."
- What's your next step if you can't get it passed/signed?

UNIQUE PROVISIONS OF ALASKA'S SDMA ACT

- ANYONE CAN HAVE ONE
  - PEOPLE DON'T HAVE TO HAVE A DISABILITY TO HAVE A SDMA
- **ANYONE** . . .
  - PEOPLE CAN BE WARDS UNDER COURT-ORDERED SUPERVISION AND HAVE A SDMA
- A PAID SERVICE PROVIDER CAN BE SUPPORTER, IF THEY DON'T DIRECTLY PROVIDE SERVICES

ALASKA WINGS

- FOCUSED ON COURT IMPROVEMENT AT FIRST
  - PROCESSES, MONITORING, REPORTING, TIMELINES (UNDERSTANDABLE)
- TECHNICAL ASSISTANCE AND SUPPORT FROM *ABA COMMISSION ON LAW AND AGING*
  - REPORTING OPPORTUNITIES AND DIRECT CALLS WERE VERY HELPFUL
- EDUCATION OF WINGS MEMBERS ABOUT SDM/SDMAs

- How many people in the room were part of a wings group? What place or priority did SDM/SDMAs have in work goals? Good ideas for using the diversity of the working group?

PILOT PROJECT

- BASED ON NONOTUCK PILOT PROJECT INDEPENDENT REVIEW
- DLC AND HOPE COMMUNITY RESOURCES (SERVICE PROVIDER AGENCY)
- BEST PRACTICES FOR DEVELOPING WRITTEN AGREEMENTS
- TRAINING AND TECHNICAL ASSISTANCE, FACILITATE WITH MONTHLY MEETINGS
- COLLABORATE AND SUPPORT GRANT APPLICATION FOR *WITH* GRANT

Hope COMMUNITY RESOURCES 50 YEARS
Bridges to Meaningful Lives

WHAT WE GOT RIGHT

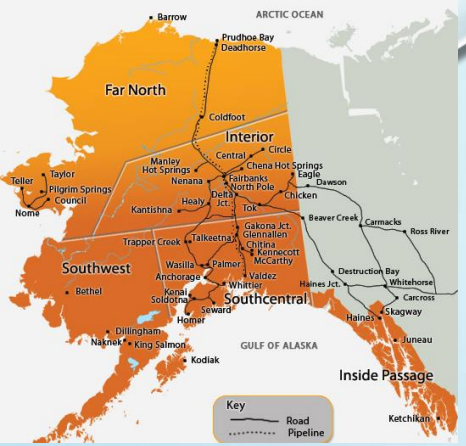
- ORGANIZATIONAL COMMITMENT TO THE WORK
- UNIVERSAL DESIGN FOR SDMAs
- WARDS CAN USE SDMAs
- UPFRONT STAKEHOLDER INPUT AND EDUCATION (REPEATEDLY AND WITH NEW INFORMATION)
- WINGS CONNECTIONS: NOVEL PARTNERS, PUBLIC GUARDIANS, COURT VISITORS AND COURT SYSTEM
- INCLUDING SERVICE PROVIDER AGENCIES AND LEGAL SERVICE PROVIDERS FROM THE BEGINNING
- FREQUENT AND MEANINGFUL COMMUNICATION WITH ALL STAKEHOLDERS

WHAT WE COULD HAVE DONE BETTER

- GREATER INCLUSIVENESS EARLIER
- CLEARER LANGUAGE ABOUT PAID SERVICE PROVIDERS AS SUPPORTERS
- ENGAGE ADULT PROTECTIVE SERVICES MORE DIRECTLY, EARLIER
- ENGAGE PRIVATE ATTORNEYS BETTER
- EDUCATE PROBATE MASTERS AND JUDGES

WHAT WE ARE DOING TO BUILD ON SUCCESSES

- EXPANDING RESEARCH, DEMONSTRATIONS, AND PILOTS
  - UAA PUBLIC HEALTH PRACTICUM STUDENTS
  - MEDICAL DECISION-MAKING SDMAs
  - COMMUNICATION SDMAs
- WIDENING THE CIRCLE
  - DIRECT INVOLVEMENT OF PEOPLE WITH DISABILITIES, OLDER ADULTS
  - STATE OFFICES TRAINED
- BUILDING ALASKA-SPECIFIC TOOLS AND GUIDES
- NATIONAL CONNECTEDNESS
  - TELECONFERENCE WITH KANSAS DD ACT PARTNERS
  - NATIONAL SPEAKERS AT SUMMIT
  - ADVICE FROM OTHER STATES



WHAT WE SEE FOR ALASKA

- STATEWIDE IMPLEMENTATION (OUTREACH VIA MOBILE CLINICS)
- SUSTAINABILITY
  - STRUCTURE, TOOLS, METHODS THAT ARE MEANINGFUL TO PEOPLE'S LIVES
- DIVERSIFICATION OF LEADERSHIP
  - FROM WITHIN RESPECTIVE STAKEHOLDER SUBGROUPS
- CHANGES IN GOVERNMENT INSTITUTIONS
  - RULES AND REGULATIONS (MEDICAID, COURT RULES, ETC.)
  - POLICIES AND PROCEDURES: PILOT PROJECT WITH APS AND ASSISTIVE TECHNOLOGY
- ADOPTION AND ACCEPTANCE BY BUSINESSES
  - LAWYERS, BANKS, HOSPITALS

BUT WHAT IF WE FAIL?
WE WON'T!

- THINK CAREFULLY ABOUT SUSTAINABILITY AND WORK BACK FROM THERE
  - WHAT WOULD IT LOOK LIKE TO HAVE USEFUL, READILY AVAILABLE SUPPORT FOR DECISION-MAKING?
- OBSTACLES ARE LIKELY TO BE . . .?
  - UNIVERSAL DESIGN IS A GOOD THING BY ITSELF, BUT ALSO . . …..
  - PROBATE BAR WAS A POTENTIAL FOR CONFLICT, SO . . ..
  - UNIQUE DEMOGRAPHICS: RURAL AND REMOTE, SO WE HAVE TO . . ..
  - GUARDIANS PUSHBACK? HOW TO HARNESS THE POSITIVES TO EXPLAIN THE BENEFITS . . .?
- DON'T THINK YOU WILL SEE ALL THE ROADBLOCKS YOURSELF; TELL EVERYONE YOUR PLANS, EVERYWHERE, AND THEN LISTEN TO ALL OF THE FEEDBACK
- Have you done a pre-mortem? What's a tough roadblock?

BUILD COALITIONS AND PARTNERSHIPS

- WHO ARE THE OBVIOUS PARTNERS? AND THE LESS-OBVIOUS PARTNERS?
  - AARP, ASAGA, PUBLIC GUARDIAN, COURT VISITORS
- WHO CAN YOU TEACH THIS MONTH?
  - KEY TO GETTING LEGISLATION PASSED
- WHO CAN WRITE AN ARTICLE FOR YOU?
- MULTI-FRONT DEVELOPMENT
  - EVEN IF OBSTACLES APPEAR IN ONE PLACE, CAN STILL BE MOVING FORWARD IN ANOTHER
  - FORCE NEW THINKING ABOUT POTENTIAL PARTNERS, NEW MOVES, NEW AUDIENCES
  - HELPFUL FOR MISSION BURNOUT

AARP
Real Possibilities

ASAGA

STAY OPEN TO VARIED PERSPECTIVES

- HUMAN RIGHT/CONSTITUTIONAL RIGHT/CIVIL RIGHTS
  - ABSOLUTELY EXPAND CONSCIOUSNESS OF RIGHTS AND WHAT DISCRIMINATION LOOKS LIKE HERE, BUT
  - BE AWARE OF WHO YOU ARE TALKING TO AND LANGUAGE THAT YOU USE
    - YOUR STATE, YOUR LEGISLATORS, YOUR COMMUNITY, YOUR CURRENT AUDIENCE
- ALSO: <u>HOW THE HECK DO WE GET IT **DONE**</u>
  - DON'T LET THE PERFECT BE THE ENEMY OF THE GOOD
    - IDEA OF PERFECT MIGHT BE ONLY YOUR PERFECT!
    - THE "PERFECT" IDEA IS A COALITION KILLER

IN THE WORDS OF THE DD SHARED VISION:

DREAM BIGGER

- IMAGINE: "HELPFUL" COUNTER AT THE POST OFFICE

- DON'T BE AFRAID TO OVER STRIVE; ANTICIPATE THE SURPRISE
  - WISH LIST: STATUTE, SUMMIT, PILOT PROJECT, APP, WEBSITE
  - STUFF THAT DIDN'T HAPPEN (yet!): CASE FILE RESEARCH, OLDER ADULTS PILOT, CARD USBs AS SWAG, MEDICAID REIMBURSEMENT, CARE COORDINATORS ENGAGED

- YODA: "DO OR NOT DO; THERE IS NO TRY."
  - THAT'S HOOEY. OR . . . **DO** TRY SOMETHING, CHANGE IT UP AND **DO** TRY IT AGAIN.
  - ONCE MORE INTO THE BREACH!

QUESTIONS?

- WEBSITE: http://dhss.alaska.gov/gcdse/pages/projects/sdma/default.aspx
- MY COORDINATES: anne.applegate@alaska.gov
- PILOT PROJECT: RICK BENJAMIN, HOPE, rbenjamin@hopealaska.org
- LEGAL SERVICES: DAVE FLEURANT, DLC, dfleurant@dlcak.org
- DD SHARED VISION: KIM CHAMPNEY, kim@champneyconsulting.com
- GUARDIANS, COURT VISITORS: LISA WAWRZONEK, ASAGA: asagaak@gci.net
- ALASKA WINGS: LISA WAWRZONEK: lwawrzonek@akcourts.us, http://courts.alaska.gov/shc/guardian-conservator/wings.htm