



CENTER FOR DEVELOPMENT & DISABILITY

UNIVERSITY CENTER FOR EXCELLENCE IN DEVELOPMENTAL DISABILITIES EDUCATION,
RESEARCH AND SERVICE

Model of Care for Cleft Lip/Palate in New Mexico

TAITE WINTER

LEND TRAINEE 2020/2021

SPEECH-LANGUAGE PATHOLOGY

Agenda

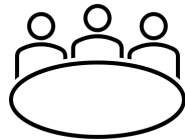


PROBLEM FRAMING:

LEND Competencies



Research & Critical Thinking



Interdisciplinary Practice



Leadership



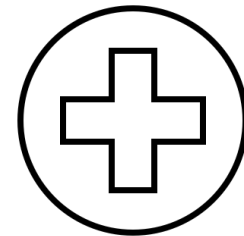
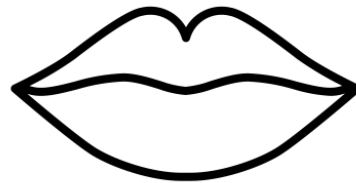
PROBLEM FRAMING:

Purpose/Questions:

- *To evaluate the model of care for cleft lip and/or palate in New Mexico through an in-depth literature review and informational interviewing process:*

WHAT IS THE MODEL OF CARE FOR CLEFT LIP/PALATE IN NEW MEXICO?

1. What is the prevalence of clefting in New Mexico?
2. What factors are unique to NM?
3. What resources and services are available to families and their children born with cleft lip and/or palate in NM?



Key:

CL = cleft lip (only)

CP = cleft palate (only)

CLP = cleft lip & palate

RESEARCH FINDINGS: Relation to LEND

Isolated cleft:

- ~ 95% of babies with **CL** with or without **CP**
- ~ 85% of babies with **CP** only
- (UC Davis Health, n.d.)

Syndromic cleft:

- ~ 5% of babies with a **CL** with/without **CP**
- ~ 15% of babies with **CP** alone
- (Stuppia et al., 2011; UC Davis Health, n.d.; Venkatesh, 2009)

Associated anomalies:

- Prevalence of anomalies + orofacial clefts = ~ 20%
 - Extremities
 - Cardiovascular
 - Other facial anomalies
- (Kamiloglu, 2019; Hadadi et al., 2017; Lilius, 1992)

PROBLEM FRAMING:

Relation to LEND

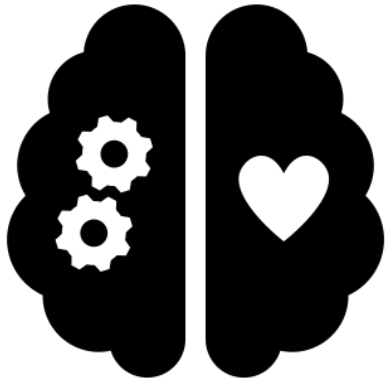
- *It is estimated that 5–30% of people born with a cleft are affected by another condition or syndrome*
- **CL/CP** is listed as a symptoms of over 300 various syndromes
 - Pierre Robin Sequence
 - Stickler syndrome
 - Apert syndrome
 - Treacher Collins syndrome
 - Van der Woude syndrome
 - CHARGE syndrome
 - DiGeorge (22q11.2 deletion) syndrome

(UC Davis Health, n.d.; CLAPA, n.d.; Kamiloglu, 2019; Proud et al., 2009; Setó-Salvia & Stanier, 2014; Stanier & Moore, 2004)



PROBLEM FRAMING: Relation to LEND

Psychiatric Disorder	Intellectual Disability	Language Disorders	Autism (ASD)	Attention-Deficit (ADHD)	Other behavioral or emotional disorders in childhood
CL	CL	CL			
CLP	CLP	CLP	CLP		
CP	CP	CP	CP	CP	CP



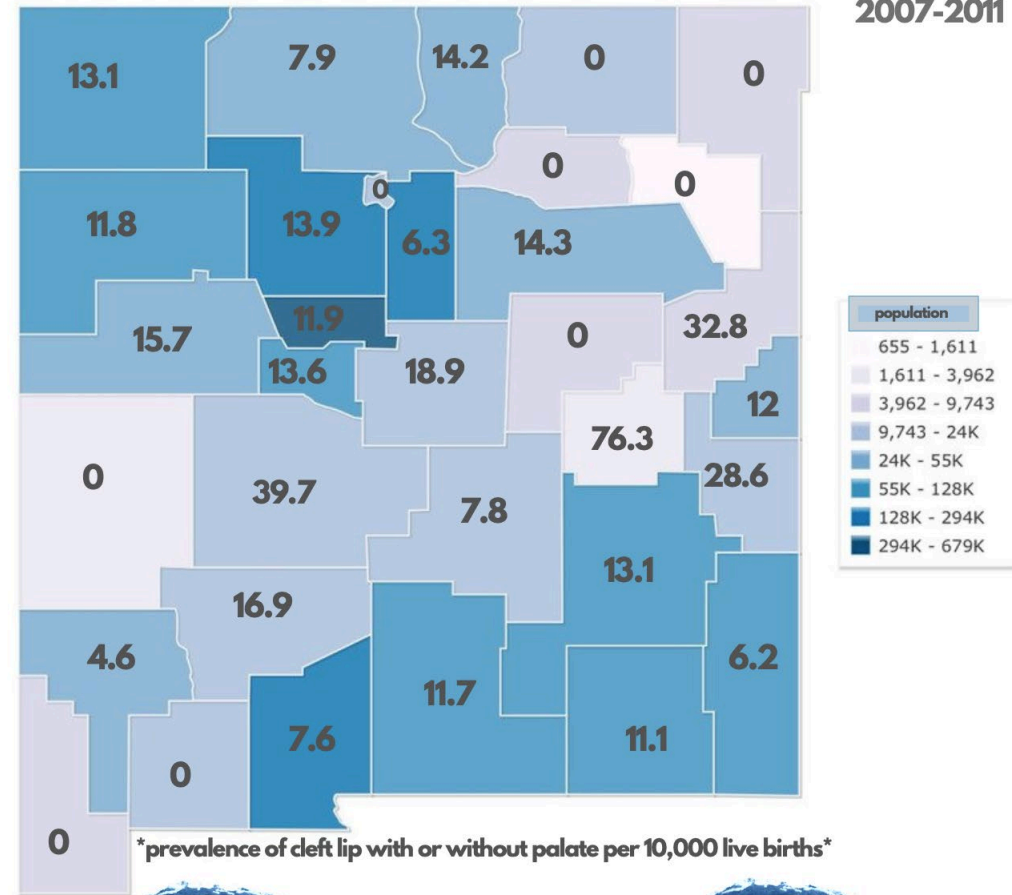
- **3xs more likely to utilize special education services!**
- Research suggests that...
 - Children with clefts are less adept readers than demographically matched peers without clefts.
 - Children with isolated **CLP** have abnormally small brains
 - Substantially decreased cerebrum (frontal lobe) & cerebellum volume

(Tillman et al., 2018; Knight et al., 2015; Collett et al., 2010; Yazdy et al., 2008; Nopoulos et al., 2007)

PROBLEM FRAMING: Prevalence

PREVALENCE OF OROFACIAL CLEFTS* IN NEW MEXICO BY COUNTY

2007-2011



New Mexico
average:

11.3 / 10,000
live births

(NM-IBIS, 2014.)

National
average:

9.82-10.63 /
10,000 live
births

(NIDCR, n.d.)
(NIDCR, 2018)

METHODS:

Information Gathering

IRB approval not necessary

- Literature review:
- *Search engines:*
 - Google Scholar, UNM Library Database, ASHA Wire
- *Search terms:*
 - cleft, cleft lip, cleft palate, cleft lip and palate, prevalence of clefting, orofacial clefts, clefts and New Mexico, model of care, etc.
- Researched cleft professionals within NM:
 - University of New Mexico Hospital (UNMH)
 - New Mexico Department of Health, Children's Medical Services (CMS)
 - Indian Health Services (IHS)
 - New Mexico Cleft Palate Center
 - El Paso Children's Hospital
 - Las Cruces / NM State

METHODS:

Information - Gathering

Interviews:

- Camille Walker, NP (UNMH)
- Susan Chacon (CMS)
- Madelyn Krassner (CMS)
- Joshua D. Allison-Burbank, Ph.D., CCC-SLP (IHS)
- Luis Cuadros, MD (NM Cleft Palate Center)



LITERATURE REVIEW: Background

What is a cleft lip/palate?

- A split or opening in the upper lip, roof of the mouth, or both
- Tissues of the lip/palate fuse during the 2nd-3rd months of pregnancy

What causes cleft?

- Family history
- Exposure to certain substances during pregnancy
- Diabetes / Obesity
- An additional syndrome present at birth
- Nutritional/Environmental factors

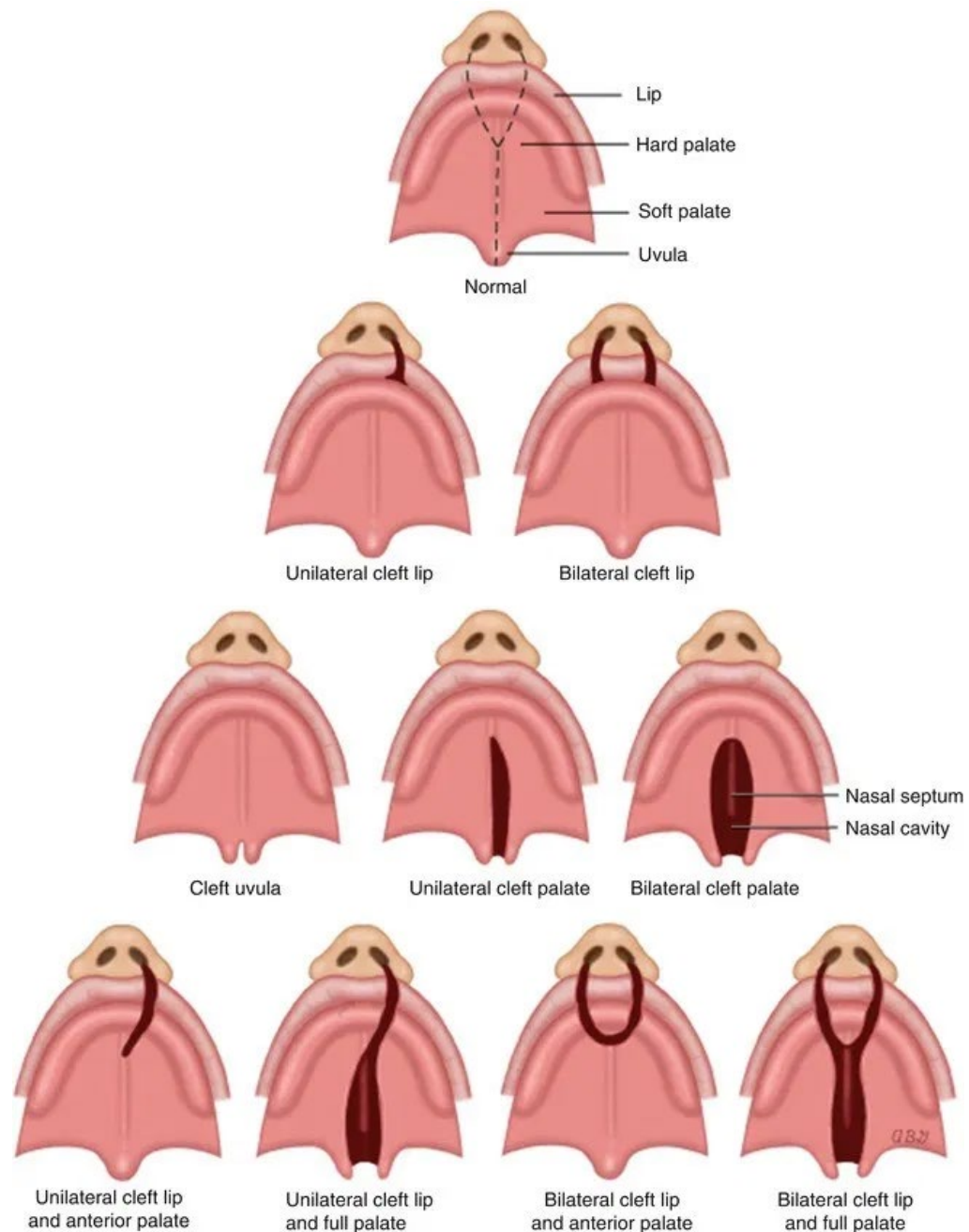
Complications:

- Difficulty feeding
- Ear infections & hearing loss
- Dental problems
- Speech difficulties
- Social-emotional/behavioral problems associated with a complex medical need and differences in appearance

Diagnosis:

- A prenatal ultrasound may detect differences in facial structures (beginning around the 13th week of pregnancy)





LITERATURE REVIEW: Background

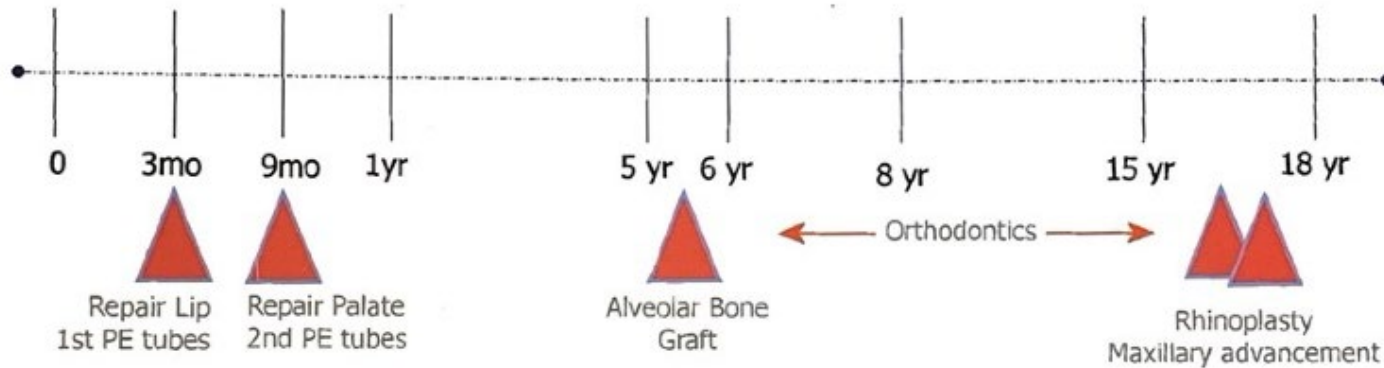
Types of clefts!
(Wilkins-Haug et al., 2012)

Cleft Lip & Palate Timeline

SPEECH & HEARING

EARLY REPAIRS

DENTAL



LITERATURE REVIEW: Background

Treatment Timeline:

- Phase 1: Early Repairs (Birth to 1 year)
 - GOAL: improve feeding and close cleft
- Phase 2: Speech & Hearing (1-8 years)
 - GOAL: improve speech & hearing measures which have a huge impact on language development & academic success
- Phase 3: Dental (6-16 years)
 - GOAL: improve dental alignment for both functional & cosmetic purposes

(Cuadros, 2015)



LITERATURE REVIEW: Background

Care Team:

Surgeons
(Plastic; Oral; ENT)

Anesthesiologists

Pediatricians

**Pediatric
dentists**

Orthodontists

Nurses

**Speech-
language
pathologists**

Audiologists

**Genetic
counselors**

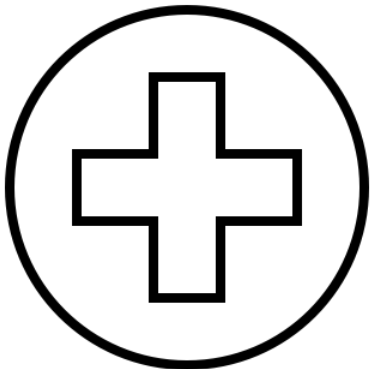
Social workers

Psychologists

Caregivers



(CDC, n.d.)



RESEARCH FINDINGS: Model of Care– Roles



University of New Mexico Hospital (UNMH)

- Major surgical repairs in ABQ by Dr. Kraai & Dr. Bennett, trained by Dr. Cuadros
- Full-functioning care-team
- Many services offered
- Located in NE ABQ
- Accepts ALL insurances & Medicaid
- Only ACPA approved care team in the state



Indian Health Services (IHS)

- Identification of children with cleft
- Outpatient services (ex: speech)
- Connecting families to services
- NO surgical procedures

Children's Medical Services (CMS)

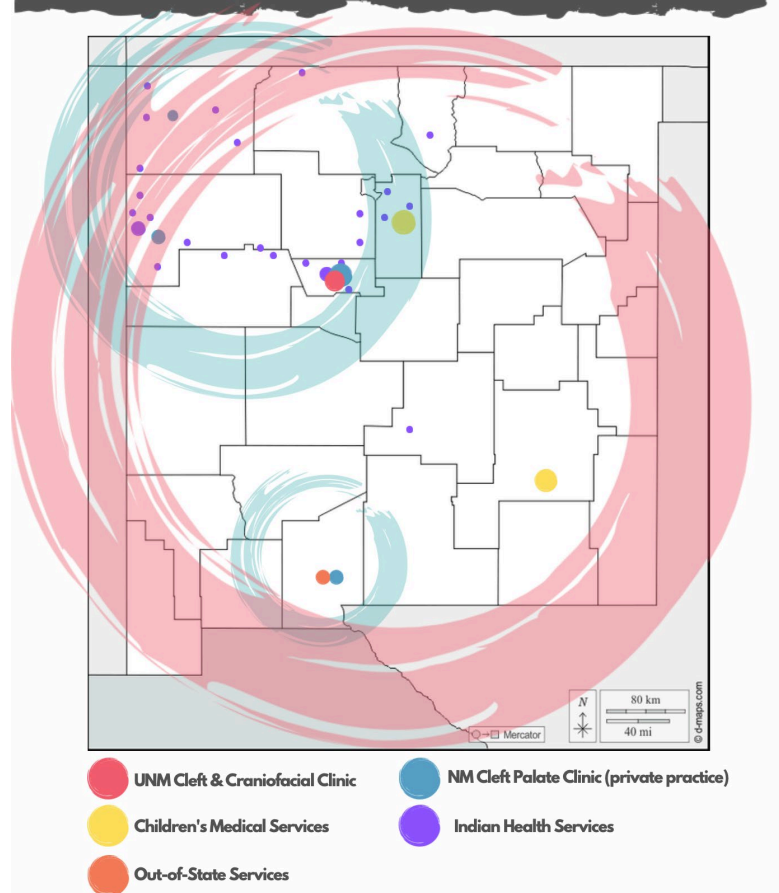
- Connecting families to services
- Annual/bi-annual check-ins
- Care coordination
- Locations: Farmington, Santa Fe, Roswell, & Las Cruces
- NO surgical procedures

New Mexico Cleft Palate Center (NMCPC)

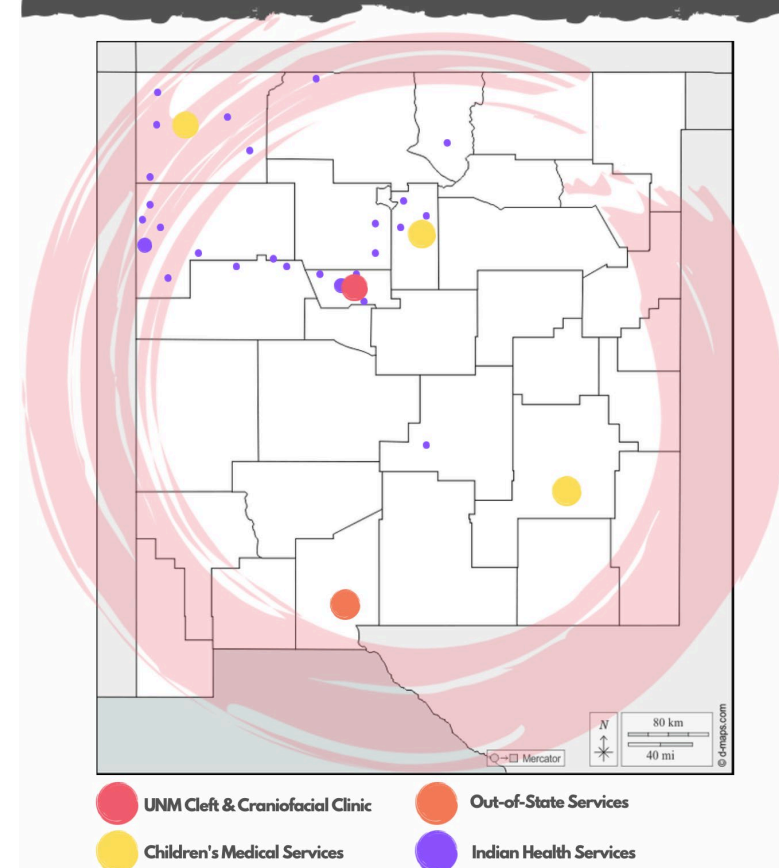
- Surgical repairs in ABQ by Dr. Cuadros
- Speech evaluations
- Outreach in rural, NE & SE regions



CLEFT CARE IN NM PRE-2021



CLEFT CARE IN NM POST-2021



RESEARCH FINDINGS:

Model of Care— Changing Roles

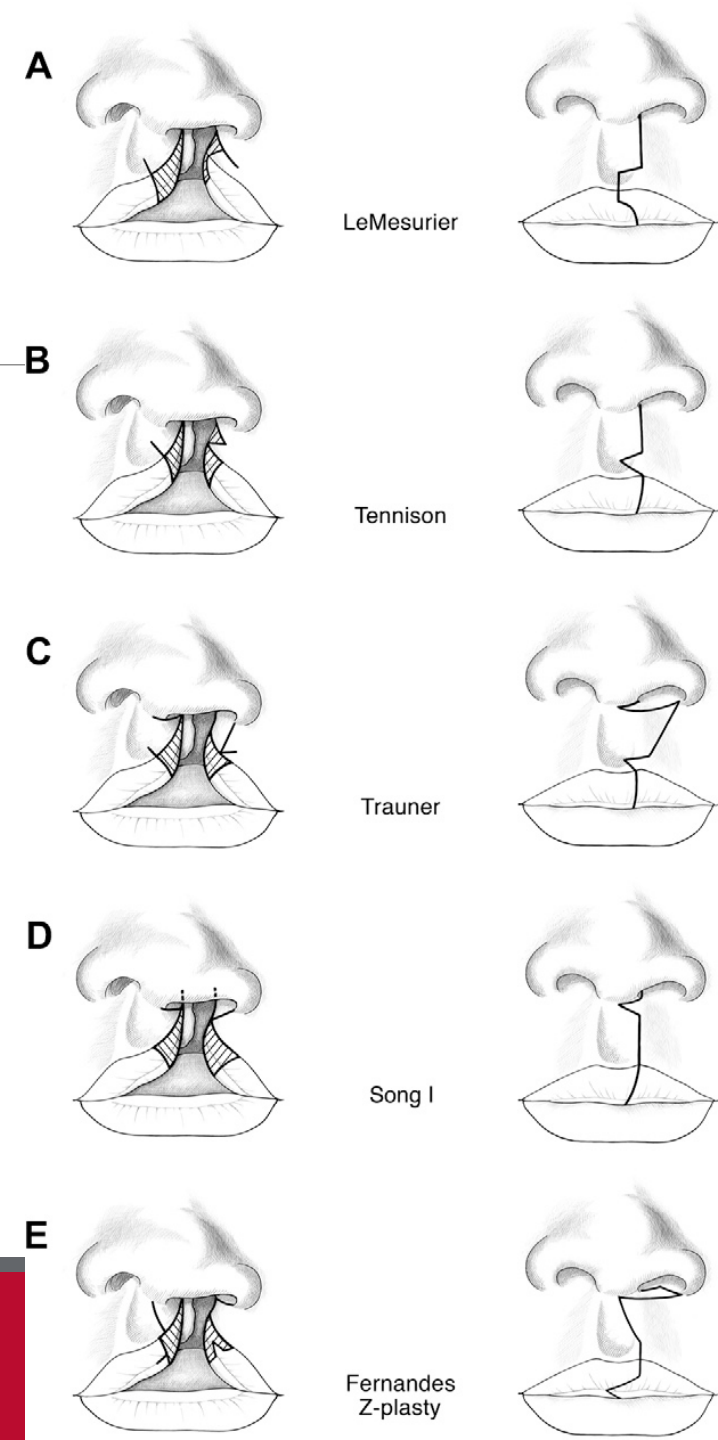
RESEARCH FINDINGS:

Differing Approaches

- Private practice VS public health care systems
- Varying surgical techniques
- Varying models of care:

American	European
No registry	Established database
Less centralized model	More centralized model
No quality control measures	Internal reviews
Priorities– multidisciplinary team, solve everything	Priorities– three main concerns: 1. Cleft repair 2. Speech 3. Dental

(Demke & Tatum, 2011; Shaw et al., 2001)

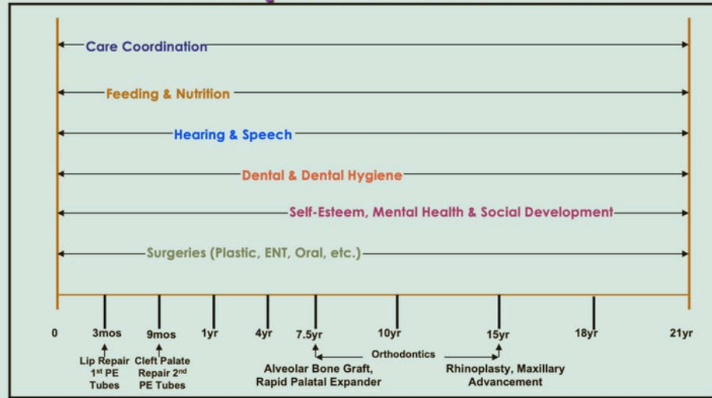


APPROACHES TO CARE

New Mexico Department of Health: Children's Medical Services (NM DOH: CMS)

public health service

Cleft Lip & Palate Timeline

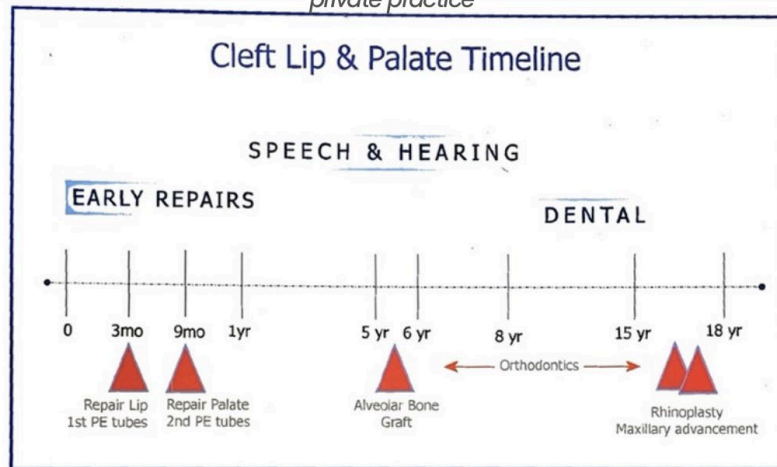


(CMS, n.d.)

New Mexico Cleft Palate Center: Dr. Cuadros

private practice

Cleft Lip & Palate Timeline



(Cuadros, n.d.)

American
Model

European
Model

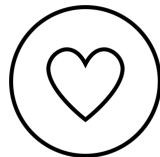
RESEARCH FINDINGS:
Differing
Approaches

RESEARCH FINDINGS:

Strengths & Challenges

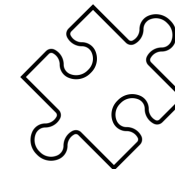
Areas of strength:

- Passionate, incredible providers
- Dr. Cuadros & UNM have high standards of care
- CMS's clinic allow families to connect with many professionals, closer to home
- Centralization of services at UNM
- Wide array of providers (especially in ABQ)

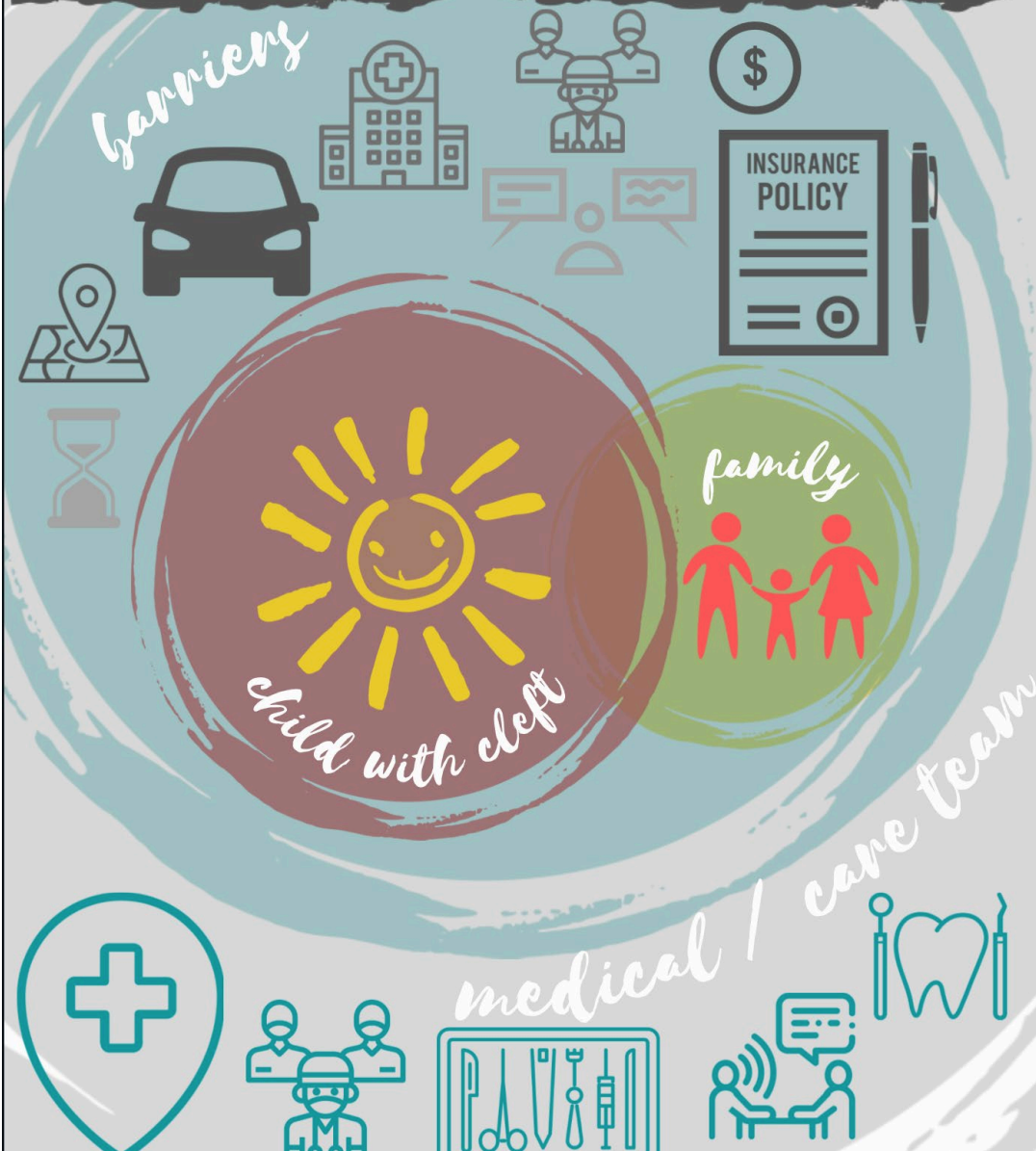


Challenging aspects:

- NM is a large & rural state
- Economics
- Lack of access to transportation/technology
- Complex network of services for families to navigate
- Insurance coverage issues
- Centralization of services at UNM
- Provider burnout/lack of quality providers



STAKEHOLDERS & BARRIERS TO CARE



RESEARCH FINDINGS:

Stakeholders

- Child with cleft lip and/or palate
- Family/Caregivers
- External Factors
- Healthcare team

CLEFT CLINICS

UNM Cleft & Craniofacial Clinics

Albuquerque, NM (1-3 /month)
at NE Heights Clinic

Children's Medical Services

Santa Fe, NM (2-3 /year)
Farmington, NM (0-2 /year)
Roswell, NM (1-2/year)

Out-of-State Services

Las Cruces, NM (1-3 /year)
at MECA Therapies with Dr. Yates of El Paso Children's Hospital

RESEARCH FINDINGS: Resources



RESEARCH FINDINGS: Takeaways

- ★ Isolated clefts and, especially, clefts associated with a syndrome present a unique intersection of neurodevelopmental needs.

The Need:

- Quality providers & services to serve rural NM, where **CL/CP/CLP** has some of its highest prevalence's
- Identification/tracking registry for children with cleft
- More professionals educated & trained to meet the needs of this population



PRODUCT: Creation



CENTER FOR DEVELOPMENT & DISABILITY

New Mexico Leadership in Neurodevelopment & Related Disabilities Program 2020-2021 (NM LEND)

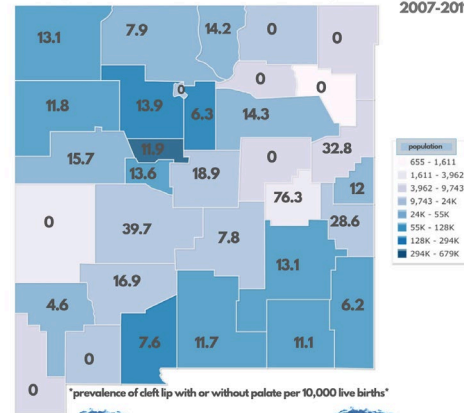
CAPSTONE PRODUCT:
Model of Care for Cleft Lip/Palate in New Mexico



Created by Taite Winter, UNM Speech & Hearing Sciences Graduate Student



PREVALENCE OF OROFACIAL CLEFTS* IN NEW MEXICO BY COUNTY



New Mexico average:
11.3/10,000 live births

(NM-IBIS, 2014.)

National average:
9.82/10,000 live births

(CDC, n.d.)

STAKEHOLDERS & BARRIERS TO CARE



CLEFT CLINICS

UNM Cleft & Craniofacial Clinics

Albuquerque, NM (1-3 /month)
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Children's Medical Services

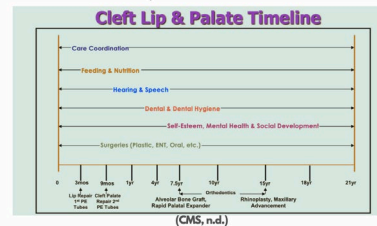
Santa Fe, NM (2-3 /year)
Farmington, NM (0-2 /year)
Roswell, NM (1-2/year)

Out-of-State Services

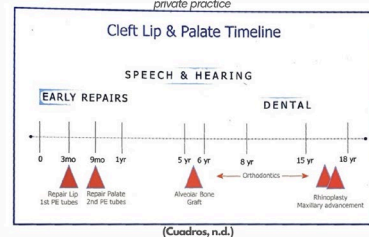
Las Cruces, NM (1-3 /year)
at MECA Therapies with Dr. Yates of El Paso Children's Hospital

APPROACHES TO CARE

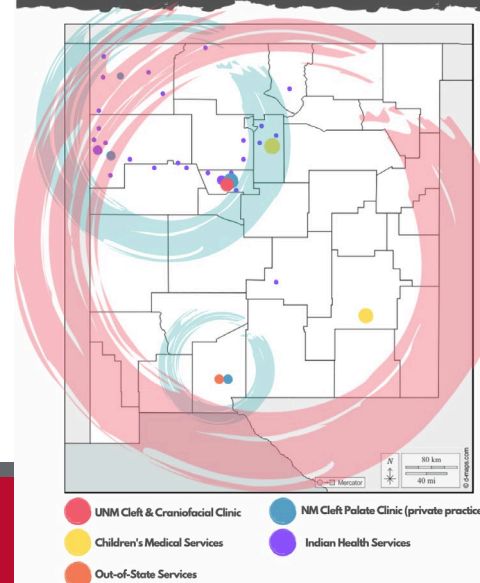
New Mexico Department of Health: Children's Medical Services (NM DOH: CMS)
public health service



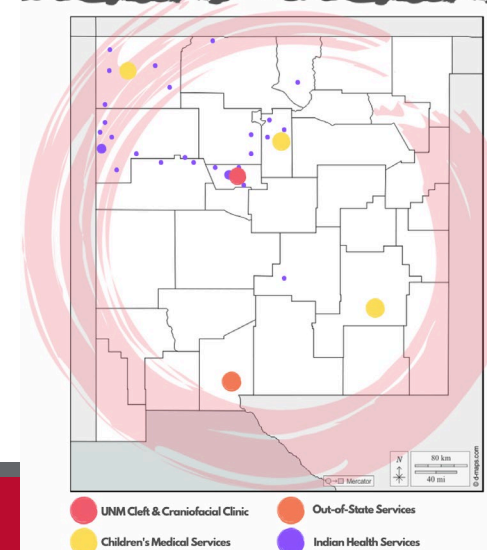
New Mexico Cleft Palate Center: Dr. Cuadros
private practice



CLEFT CARE IN NM PRE-2021



CLEFT CARE IN NM POST-2021



PRODUCT: Dissemination

NM LEND trainees– April 30, 2021 @ 10:45 AM

UNM Speech & Hearing Sciences Department (faculty, student, & alumni) @ 3:30 PM

Plans to share my product with any and all who are interested after listening to this presentation

Will be forwarding my final product/presentation to all individuals/providers who are stakeholders in cleft care in NM



CONCLUSION: Key Learning

- Cleft care is complex and New Mexico has unique needs!
- The model of cleft care in NM is in a state of transition!
- Articulating my values, organizing/conducting research, and presenting findings!

CONCLUSIONS:

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CONCLUSIONS:

References

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QUESTIONS

