

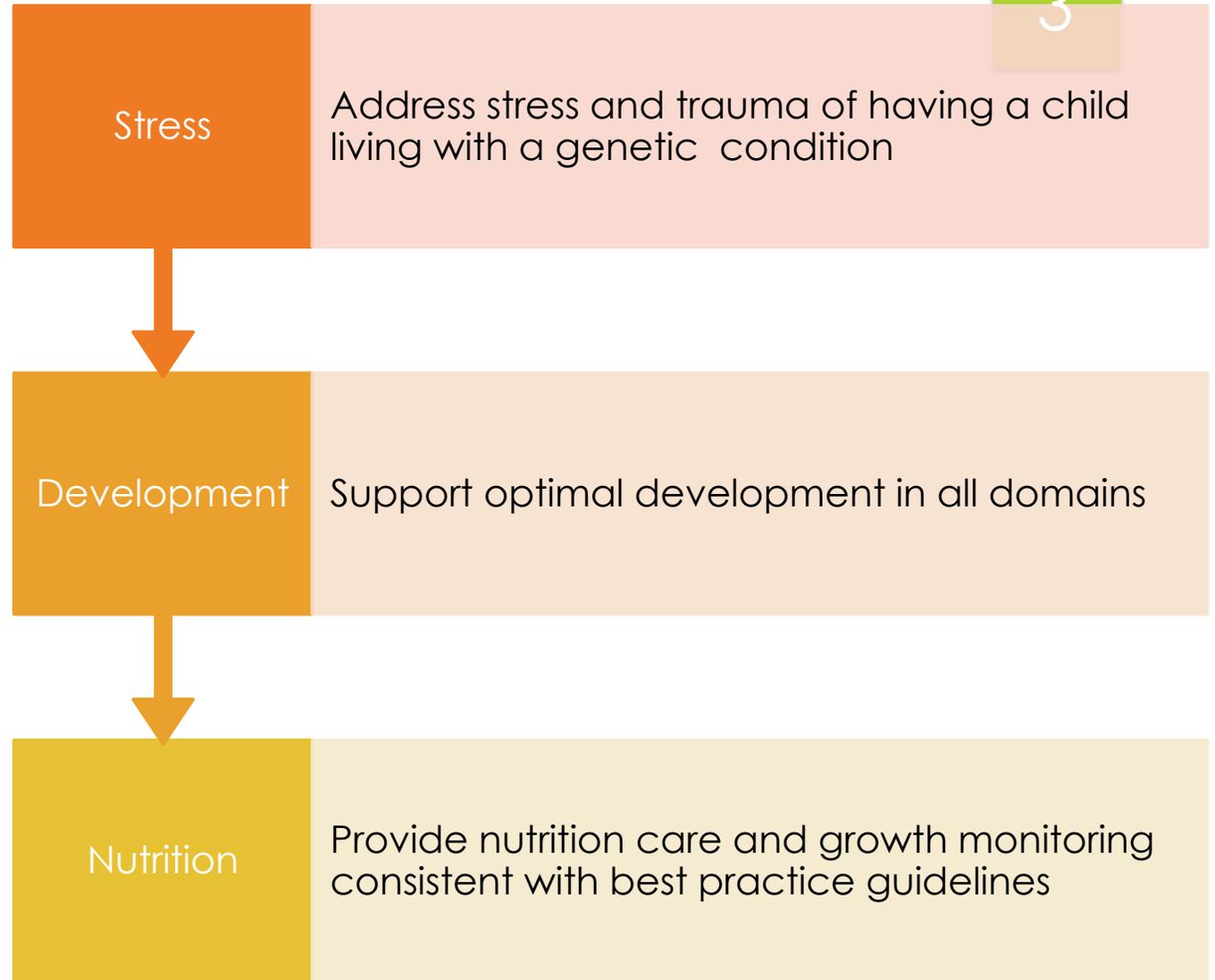
Transdisciplinary approach to nutrition management for children living with genetic conditions

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Opportunities

- ▶ How can community nutrition services provided through EI services, outside of routine genetic clinic appointments, provide child and family centered care and improve outcomes
- ▶ How would you use Quality Improvement (QI) to address challenges in managing genetic conditions in rural areas
- ▶ How does telehealth enhance all aspects of genetic care
 - ▶ Perceptions of quality of care
 - ▶ Access
 - ▶ Frequency of visits
 - ▶ Monitoring

Connecting the dots through Transdisciplinary Early Intervention (EI) Services for Children with Genetic Conditions



Early Intervention Model

- ▶ Coaching model for caregivers
- ▶ Support for developmental progress across all domains
- ▶ Transdisciplinary-therapists have overlapping and complimentary skills
- ▶ Strategies are imbedded in daily routines to maximize growth
- ▶ Home visiting model-services provided in authentic environments
 - ▶ Home, school, daycare, community settings

New Mexico Digital Divide

- ▶ NM 5th largest state geographically
- ▶ 32 of 33 counties designated as Health Provider Shortage Areas (HPSA)
- ▶ 30% of the population lives in rural/frontier areas
- ▶ Ranked 49th in broadband access and only 12.5% have access to low-cost broadband (\leq \$60/month)
 - ▶ <https://broadbandnow.com/New-Mexico> (accessed October 3, 2021)
- ▶ Best access is in the NW and SE regions
- ▶ Tribal areas with even greater challenges

Perceptions of Telehealth in EI model

- ▶ Context
 - ▶ EI is a coaching model-not direct service
 - ▶ Families initially must be introduced to coaching and strategies imbedded into daily routines
- ▶ Telehealth
 - ▶ Families may not have prior experience with telehealth
- ▶ Coaching via telehealth
 - ▶ Requires caregivers to be actively engaged
 - ▶ Families prefer in person, see telehealth as a supplement to services
 - ▶ Prepare for visit –toys; position of digital device; expectations for the visit;
 - ▶ Therapists use props to demonstrate strategies
 - ▶ Yang H et al., Family perspectives toward using telehealth in early intervention. Journal of Developmental and Physical Disabilities-published online May 11, 2020 (Springer) <https://doi.org/10.1007/s110882-020-09744-y>

Access

- ▶ Opportunities
 - ▶ Rural
 - ▶ Pandemic restrictions
 - ▶ Bad weather
 - ▶ Family illness
 - ▶ Ease of scheduling (for providers)
 - ▶ Addresses transportation barriers
- ▶ Challenges
 - ▶ Reliable internet
 - ▶ Digital device-smartphone, tablet, computer

Frequency of visits

- ▶ One genetic provider in NM
 - ▶ Backlog and long wait times for initial and follow up appointments
 - ▶ Outreach clinics around the state
 - ▶ Family travels to more convenient location for some visits
 - ▶ Dietitian working with the clinic has limited capacity-especially for children without a metabolic component to their genetic condition
- ▶ EI nutrition provider
 - ▶ Address complex nutrition care in home environment
 - ▶ Include other EI providers in coordinated nutrition care (see handout)
 - ▶ Consistent care

Example-Genetic Conditions with Nutrition Concerns

Conditions	Growth	Overall Development	Feeding-skill	Co-occurring Medical Issues	Early Intervention (EI)
Micro-Deletions-Duplications -Prater Willi -Cornelia de Lange -Williams -DiGeorge	Short stature LBW IUGR Delayed bone age Weight gain	Global delay Intellectual disability hypotonia	Dysphagia Aversion Dental and palate differences	Cardiac Seizures Renal Food allergy ADS/ADHD	OT PT SLP DS SW
Trisomy 21					
Rare Disorders					

Monitoring

- ▶ More frequent nutrition visits allow for changes in care as needed
 - ▶ Growth monitoring
 - ▶ Support for changes in feeding skills
 - ▶ Follow best practice guidelines for routine care for children with genetic conditions

Cost

- ▶ Reimbursement in pandemic changed to reflect in-person rates
- ▶ No change in provider time with family
- ▶ Travel time decreased for providers-may increase capacity
 - ▶ Not necessarily true for clinic-based providers
 - ▶ Portney DS et al., Understanding the cost savings of video visits in outpatient surgical clinics. *mHealth* 2020;6:32.

Quality Improvement Lens

- ▶ PDSA-Plan do Study Act
 - ▶ Can be used for systematic changes or individual patient care
 - ▶ See attached handout
- ▶ QI allows for reimagining how to use the resources already in place, including staff
- ▶ Acknowledges that each situation may require unique approaches
- ▶ Allows for providers and families to partner in approaches to care
- ▶ Allows providers and provider agencies to alter delivery approaches to support family/child centered care
- ▶ <http://www.ihl.org/education/ihlopenschool/Courses/Documents/QI102-FinalOnePager.pdf>

Family stories

Reflection

- ▶ What was new or surprising about our discussion today?
- ▶ What questions have emerged after our discussion today?
- ▶ What will you use right away in your practice?

Questions and Comments

Thank you!