

# Raising a Child with Developmental Differences in Kyrgyzstan

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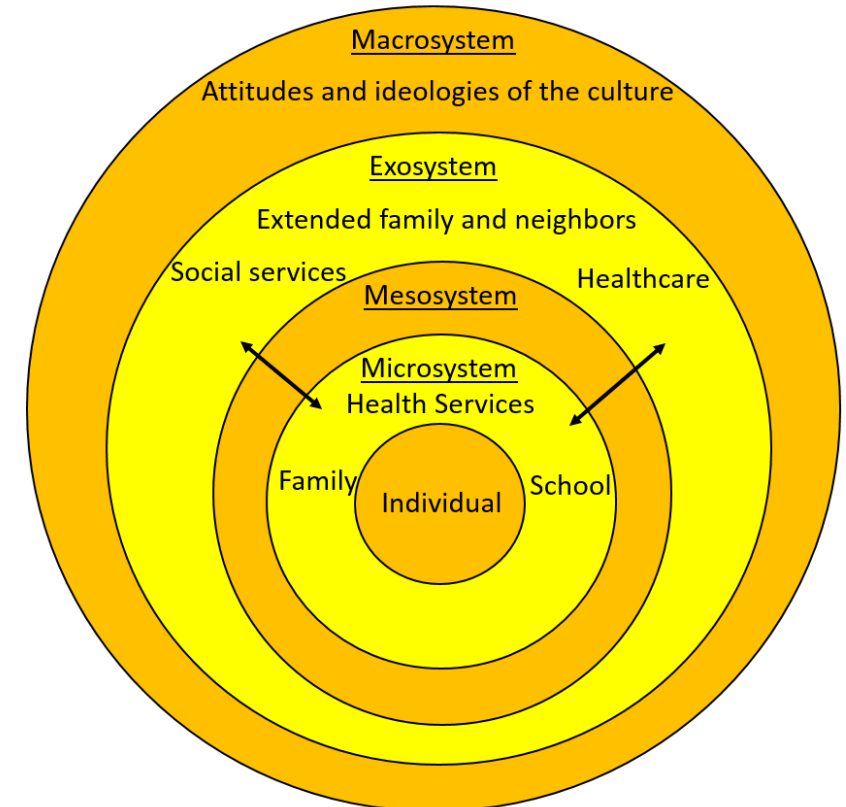
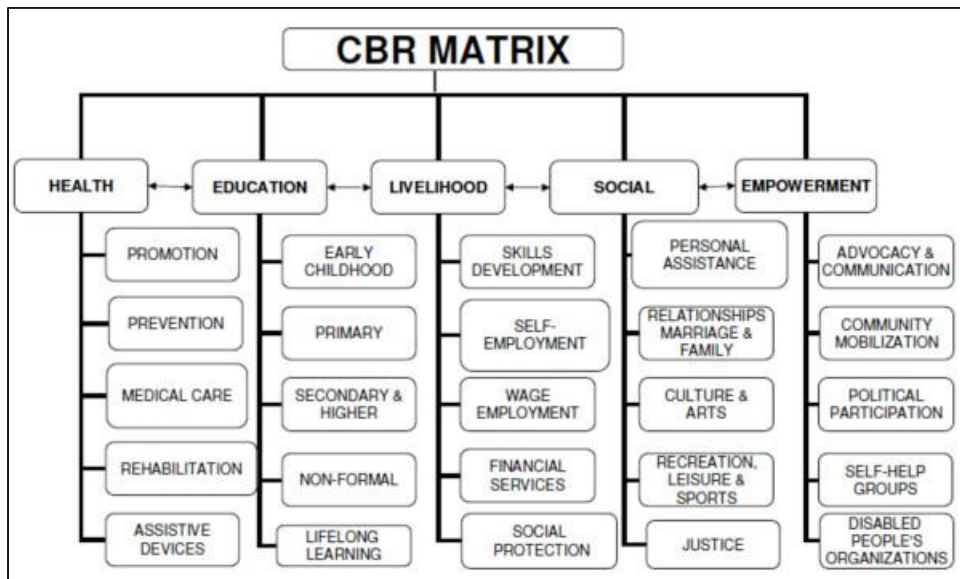
# Background: The case of Down Syndrome in Kyrgyzstan

- **Kyrgyzstan**
  - Population: 6 million
  - HDI: 125/187
  - Religion: Sunni Muslim
  - Capital: Bishkek
- **Cultural influences and disability**
  - Communal, shame based culture
  - Soviet legacy: Defectology model
  - Downs or Sunshine Children?
- **Sunterra**
  - Organization for parents of children with Down Syndrome
  - Parent support, informational resources, visibility advocacy, groups for children
- **No occupational therapy**



# Theories and Frameworks

- Examining disability and participation from an **environmental perspective**
  - **Bronfenbrenner's Ecological Systems Model**
  - **The Capabilities Approach**
  - Community Based Rehabilitation Matrix
  - International Classification of Functioning, Disability, and Health (ICF)



# Purpose and Aims

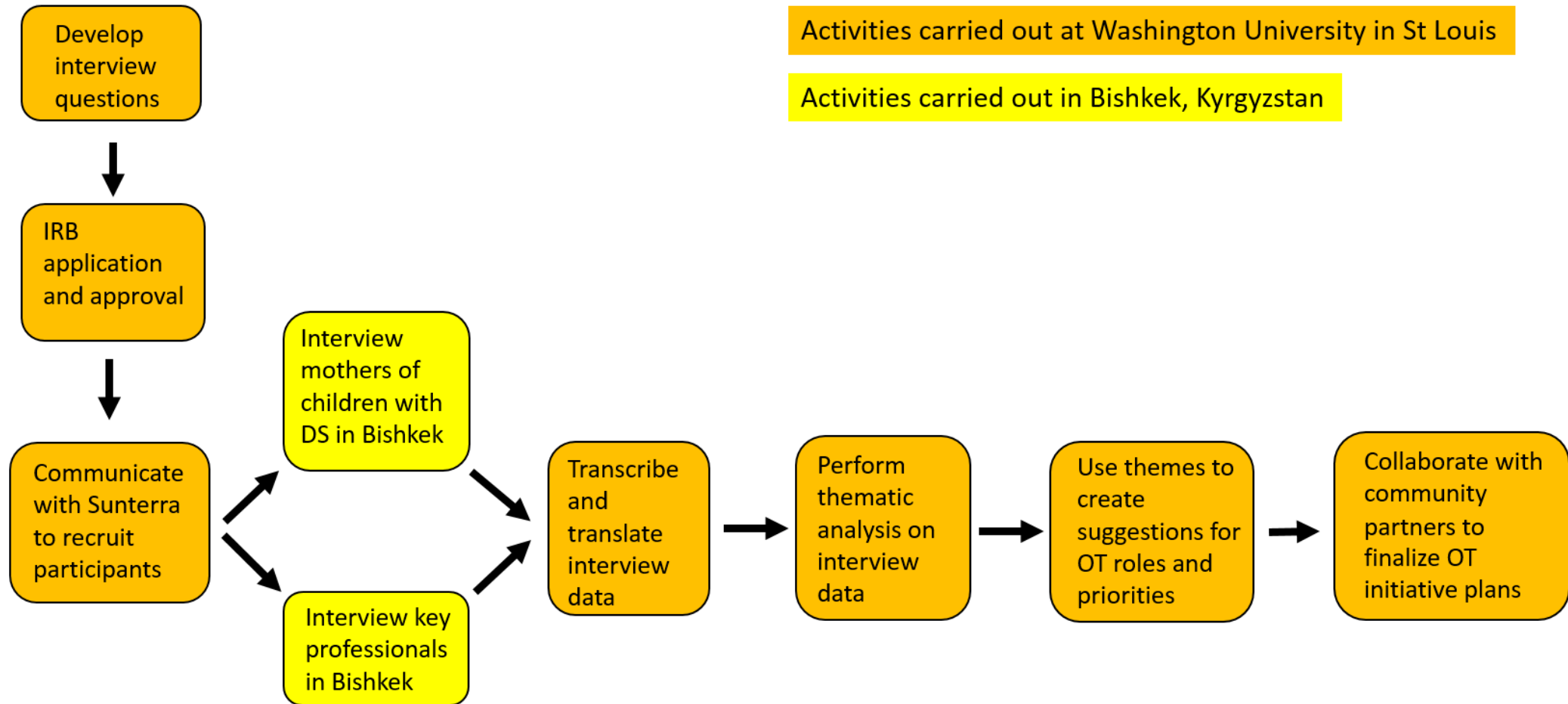
**Purpose:** Explore cultural perceptions of disability through experiences of mothers of children with Down Syndrome and investigate culturally grounded OT roles in Bishkek

Aim 1: Interview moms of children with Down Syndrome about supports, services and needs

Aim 2: Interview professionals who work with children with disabilities about supports/services for moms

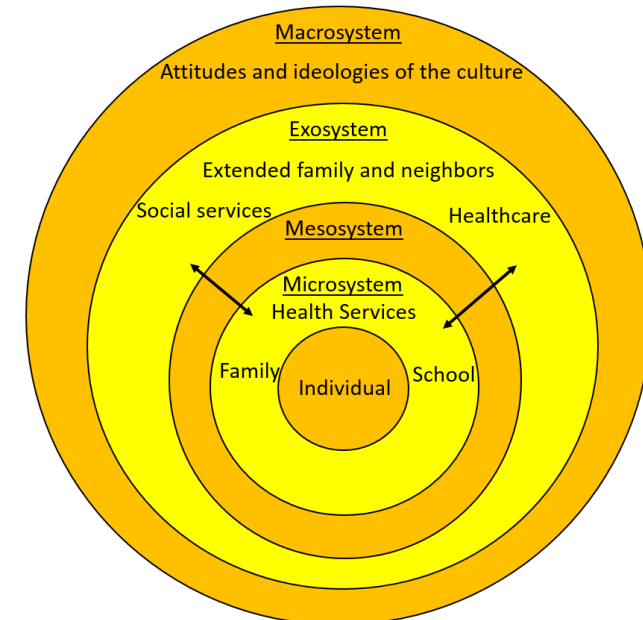
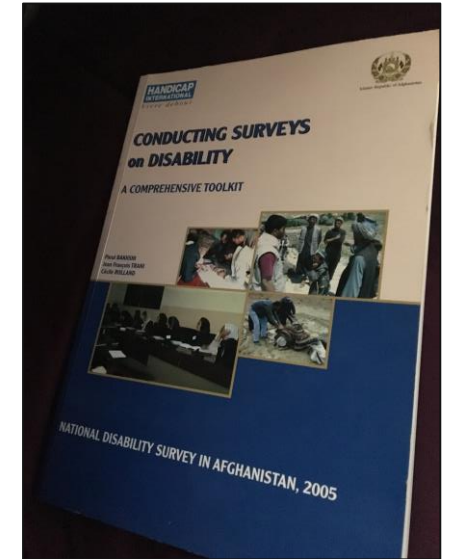
Aim 3: Reflect on possible roles for OT in Down Syndrome communities in Bishkek

# Methods



# Interview questions:

- Participatory approach
- Russian language interviews
- **Moms group:**
  - Demographics
  - Cultural attitudes toward disability
  - Supports/services: social, healthcare, education
  - Goals/concerns
- **Professionals group:**
  - Professional role
  - Cultural attitudes toward disability
  - Barriers/Supports for moms
  - Mom goals/concerns
- All questions were reviewed by community partner and a cultural reviewer to verify cultural appropriateness



# Participants

- **Moms group**

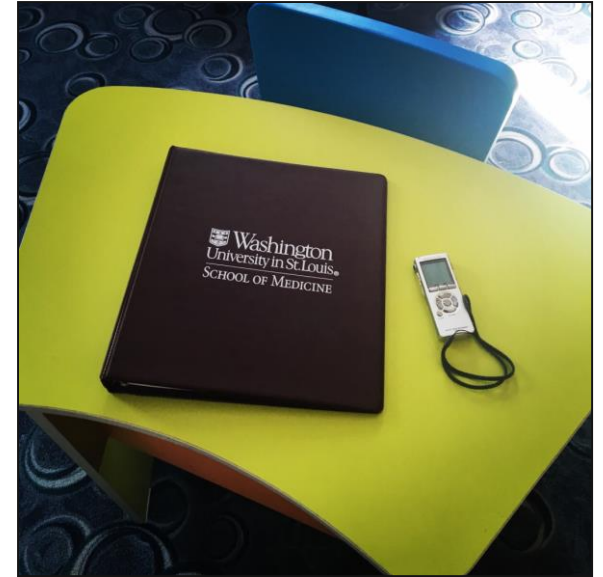
- Demographics:

- 25-41 y/o
- 3 children
- Child with Down Syndrome 4-7 years old
- Married, living with husband, children, sometimes in laws

- **Professionals group**

- Roles:

- Director of Sunterra
- Logoped- defectologist
- Expatriate OT
- Professor at American University of Central Asia

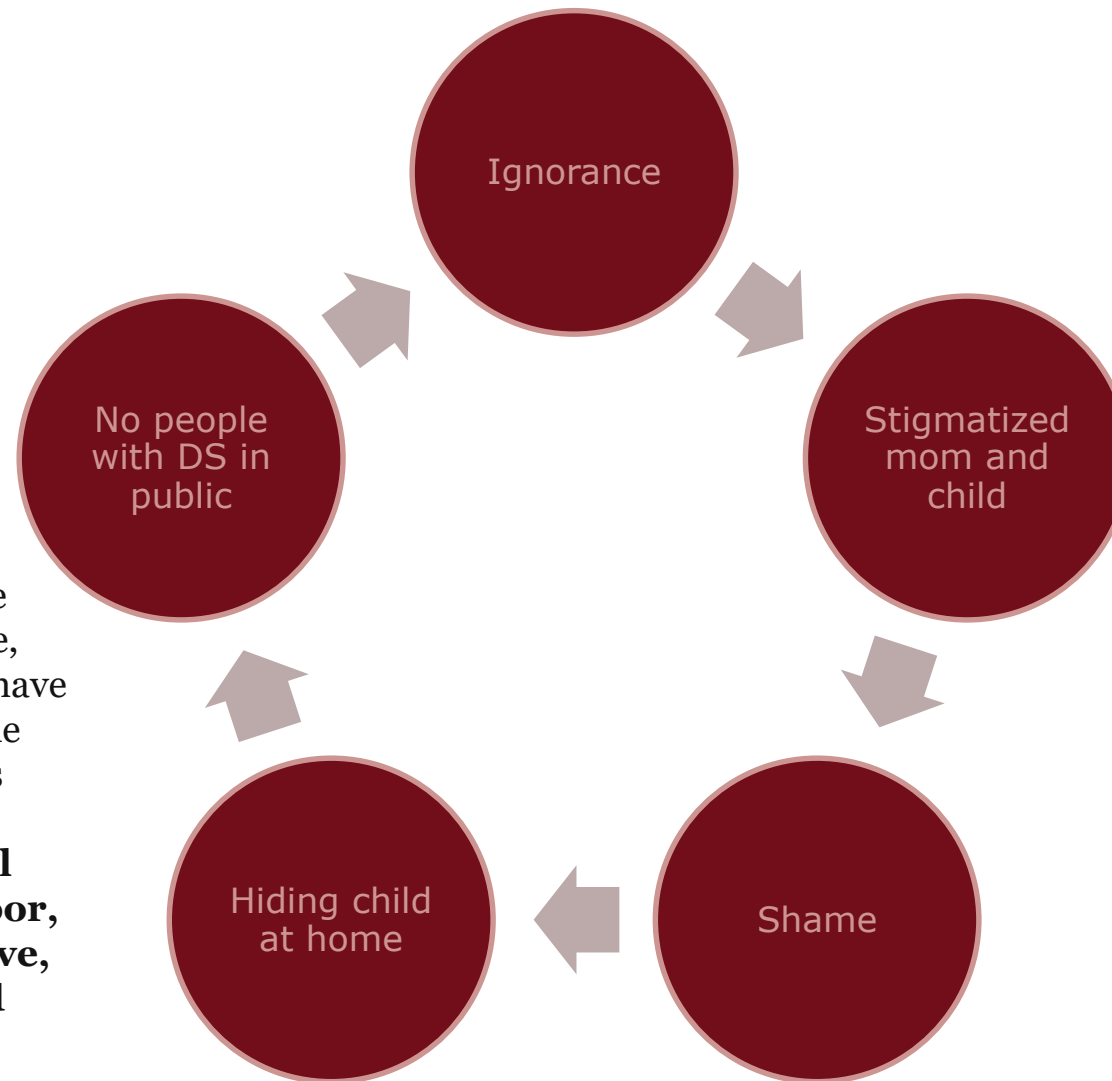




# Cultural attitudes toward Down Syndrome: defectology in practice

Culturally, too, children with Down Syndrome in the Soviet Union stood out because of their appearance. **Most of the time they were hidden away somewhere.** And we have some of that left in some places.

“they expect abnormal behavior. In our country the expectations are all negative, because if you say that you have a child with Down Syndrome more often than not there is this "aa, oo" and **people expect that the child will throw himself on the floor, scream, drool, misbehave, and just not understand anything**”



“No one knew what it was. **We had never even met these children** we had never seen them or even heard what it even was we had no idea.

“Even in social media you can see them- they’ll say **“oh you shouldn’t have smoked or drank during your pregnancy, you would have had a normal child”**”

# Mom perspectives

- **Mom explanation of Down Syndrome**

- “his down syndrome ... but I think about it like he just has a little tail like girls have ponytails, just like that my son has Down Syndrome just like a tail behind him always, it bothers us a little sometimes but basically **our little tail goes unnoticed**”
- Not a disease

- **Word choice**

- Sunshine children
- “we”, “us”, “our development”

- **Mom goals:**

- Education, independence, starting own family, socialization, physical activity, understand diagnosis, learn to drive

- **Mom concerns:**

- Societal stigma, behaviors, speech development, money, future

# Supports:

- **Social**

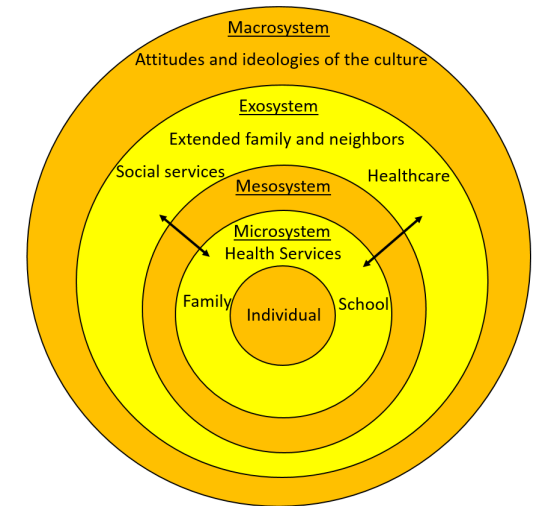
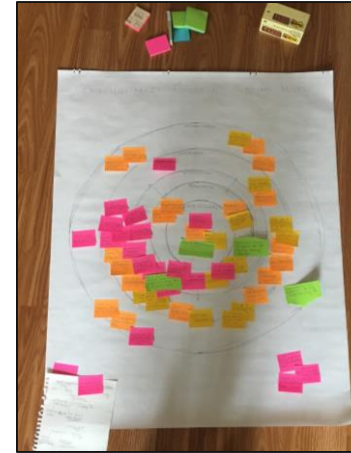
- Family: crucial role of **mothers in law**
- Sunterra: **mom-mom support**

- **Healthcare**

- Professionals: primary care, geneticist, neuropathologist, masseuse
- Passing the disability commission
- Negative experiences: "the nurses said "**oh, she will be like a vegetable**""
- Positive experiences: "she intentionally came, talked to me, and said "**there are parents with children like that, you can go talk to them**""

- **Education**

- Professionals: Logoped-defectologists
- Negative experiences: "**we don't take children like that**"
- Positive experiences: "the only kindergarten where we go, they are the only ones who said "come on in, we'll see how she behaves herself."



# Services: Using the Community Based Rehabilitation Matrix



Health	Education	Livelihood	Social	Empowerment
Promotion	Early Childhood	Skills development	Personal Assistance	Advocacy + communication
Prevention	Primary	Self employment	Relationships, marriage, and family	Community mobilization
Medical care	Secondary	Wage Employment	Culture and arts	Political Participation
Rehabilitation	Non formal	Financial services	Recreation, leisure, and sports	Self help groups
Assistive devices	Lifelong learning	Social Protection	Justice	Disabled people's organizations

\*Sunterra

# Summary of needs: the professionals' perspective

- **Professional parent support and education:**
  - “There's **no place** where Mom can take a child except a parents' association where a psychologist or a special educator will tell them everything will be okay with your kid”
  - **Russian language literature:** “the sources were using ... such **humiliating speech** that they have mental retardation, mentally retarded and very very negative descriptions”
- **Function focused action:**
  - “There are complexities in that, firstly **we do not have a lot of specialists**, speech therapists, special educators, physiotherapists- we practically don't have any of them. We definitely don't have occupational therapists, people do not even know what it is, that is”
- **Missed opportunity for early intervention:**
  - “I really I think that's ...a very big problem in this country is that **we don't have a system of early education support or early intervention** ...so this is one of my concerns because studies show that this is the most important time in the development of a child especially with children with Down Syndrome”

# Occupational therapy: A paradigm shift from defectology to capabilities

- **"The primary goal of occupational therapy is to enable people to participate in the activities of everyday life.** Occupational therapists achieve this outcome by working with people and communities to enhance their ability to engage in the **occupations they want to, need to, or are expected to do**, or by modifying the occupation or the environment to better support their occupational engagement".
- **Capabilities approach:**
  - Mom functioning:
    - Parenting their child with Down Syndrome
  - Child functioning:
    - Socialization, education, community participation

# Insights

- Cultural attitudes toward disability in Kyrgyzstan are an **environmental barrier** for mother/child dyad
- Community organizations like Sunterra **offer many supports to fill in the gaps**
- There is a **specialist role for OT in community organizations** to support mom and child capabilities and bring sunshine children out of hiding and out into the light

# Future directions: in development

- **Fall 2019**
- **Professional parent support and education**
  - **Individual level:** Guiding moms on how to support their child's development, parental empowerment and training
  - **Community level:** Collaborating with community partner to create reliable, capabilities focused Russian language resources
- **Early intervention**
  - **Individual level:** collaborating with Sunterra and providing individual and group early intervention services
  - **Community level:** collaborating with logopedes, teachers, and other professionals to build capacity for early intervention programming