

Promoting Service Access and Equity in Inland Southern California: A Community of Practice Approach to Reduce Caregiver Burden and Support Connection to Regional Center

Presented by Helen Setaghiyan, B.A. & Meghna Patel, B.S.



My Background



Fran Goldfarb



Helen Setaghiyan



Guadalupe Lorena Eaton



Lucia Babb



Dr. Christine Mirzaian

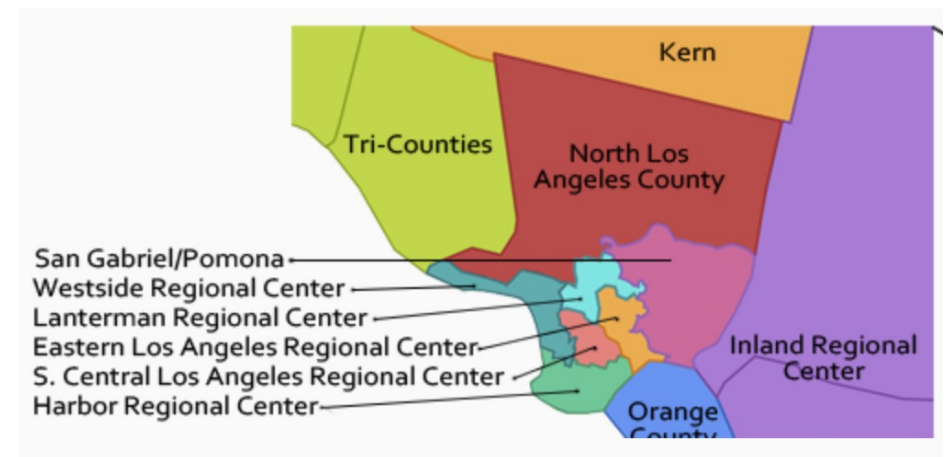


Rita Vasquez

My Background

“Parent Navigators to Increase Service Linkage in a General Pediatrics Clinic”

- Funded by The CA DDS
- Facilitated connection to Early Start & Lanterman Act services across all 7 LA County Regional Centers
- Developed RC referral guides for the LA County Dept of Public Health
- Hosted parent training sessions on Regional Center, Special Education, Mental Health Awareness, etc.



Project Background

The Inland Regional Center (IRC)

- Riverside and San Bernardino Counties
- Serves over 42,000 individuals¹
- largest geographic area

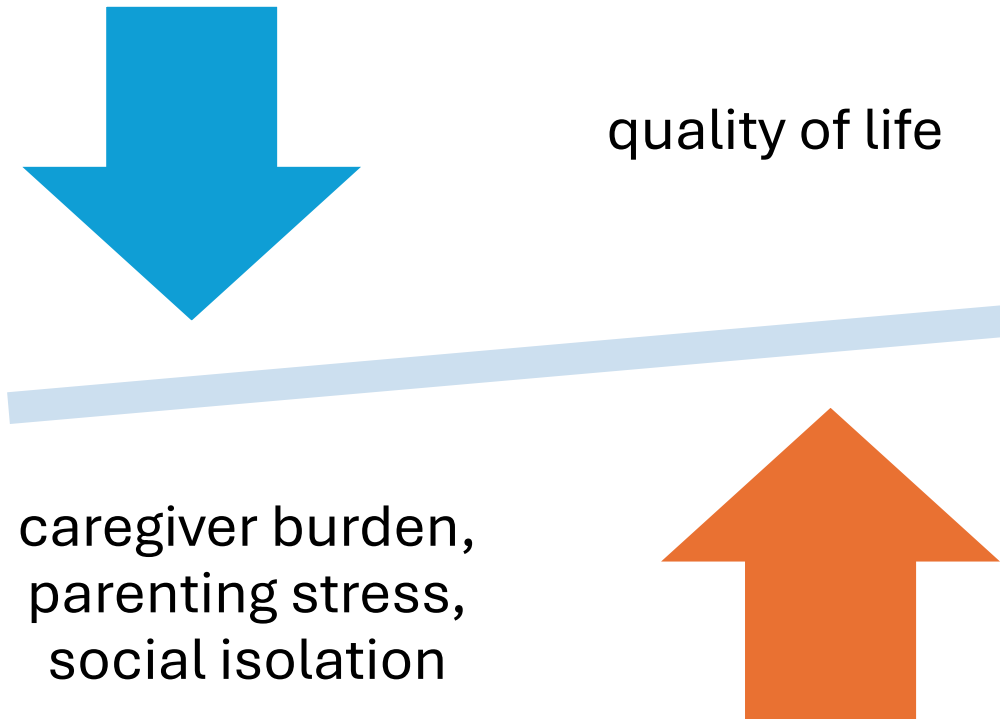
What complicates parental attempts to access Regional Center and related services in Riverside County?

- Financial, language, cultural, & practical barriers²
- Limited service providers available throughout the IE



Project Background

Parents of children with
NDD experience:³⁻⁵



Statement of Need

Existing Standard of Care

- Professional services have been shown to reduce parental stress⁶
- Time constraints limit pediatricians' ability to f/u on referrals⁷
- No standardized bridge between parents and professional services

Existing Peer Support Programs

- Promote parent empowerment and coping skills
- Lack structured curriculum for learning practical skills^{8,9}

We have identified an opportunity to use a structured framework which incorporates measurable outcomes to support parents

Framework: Community of Practice



domain

area of shared
interest

Framework: Community of Practice



domain

area of shared
interest



community

relationship built
through discussion
& activities

Framework: Community of Practice



domain

area of shared
interest



community

relationship built
through discussion
& activities



practice

shared knowledge,
stories, skills, and
tools developed



Purpose

To improve access to Regional Center and related services and reduce caregiver burden through a Community of Practice Framework.

Research Question

As a novel group intervention, how do communities of practice impact service utilization and caregiver burden inventory (CBI) scores amongst caregivers of children (≥ 2 years) with DD or suspected DD from general pediatrics clinics in Inland Southern California?

Hypothesis 1: Communities of Practice improve service utilization for children with DDs

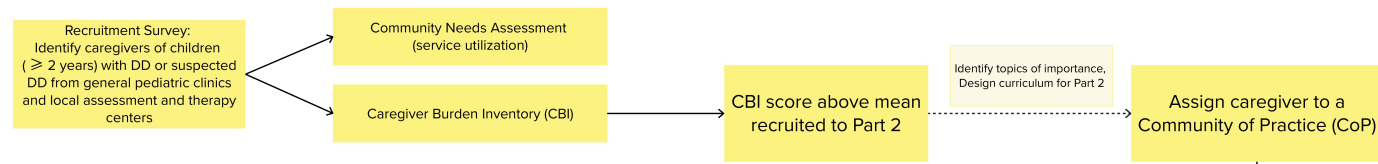
Hypothesis 2: Communities of Practice mitigate primary caregiver burden

Hypothesis 3: Communities of Practice provide the right balance of structured and unstructured interaction for participants' collaborative inquiry and growth

Project Description

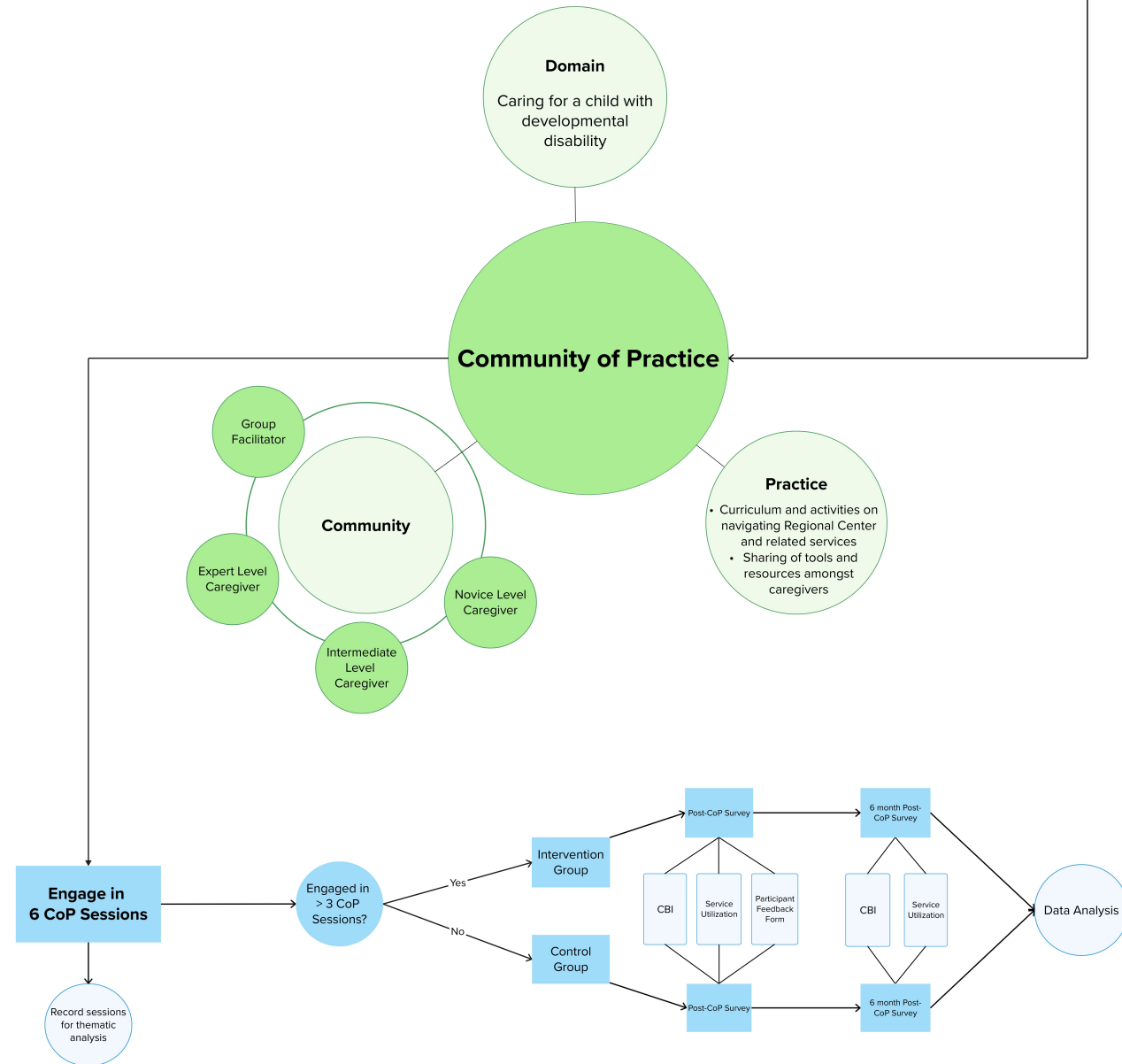
Part 1

Recruitment & Program Design

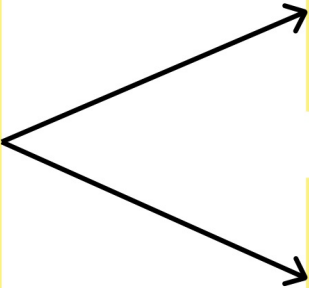


Part 2

Engage in Intervention



Recruitment Survey:
Identify caregivers of children
(≥ 2 years) with DD or suspected
DD from general pediatric clinics
and local assessment and therapy
centers



Community Needs Assessment
(service utilization)

Caregiver Burden Inventory (CBI)

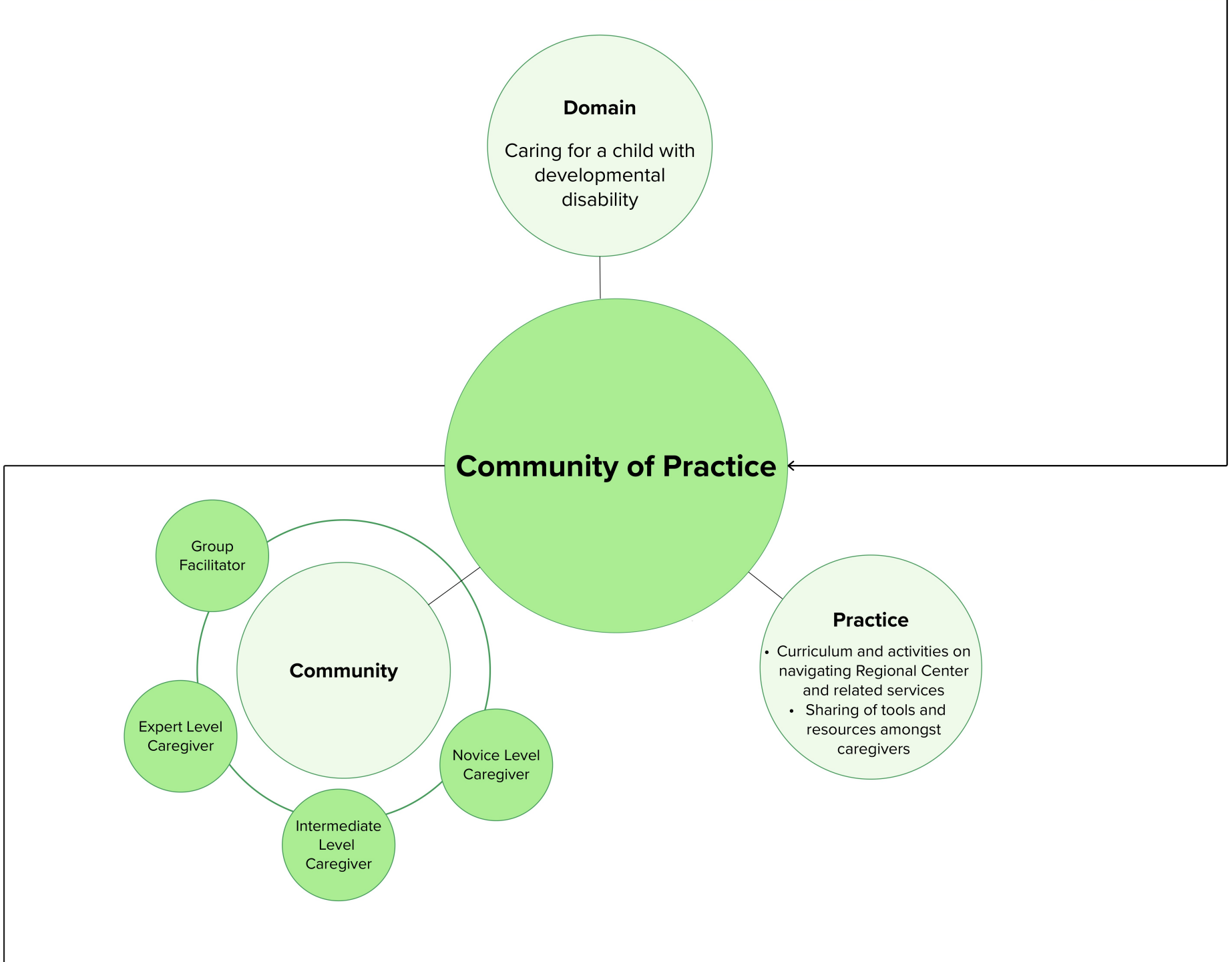


omain
or a child with
enmental

CBI score above mean
recruited to Part 2

Identify topics of importance,
Design curriculum for Part 2

Assign caregiver to a
Community of Practice (CoP)

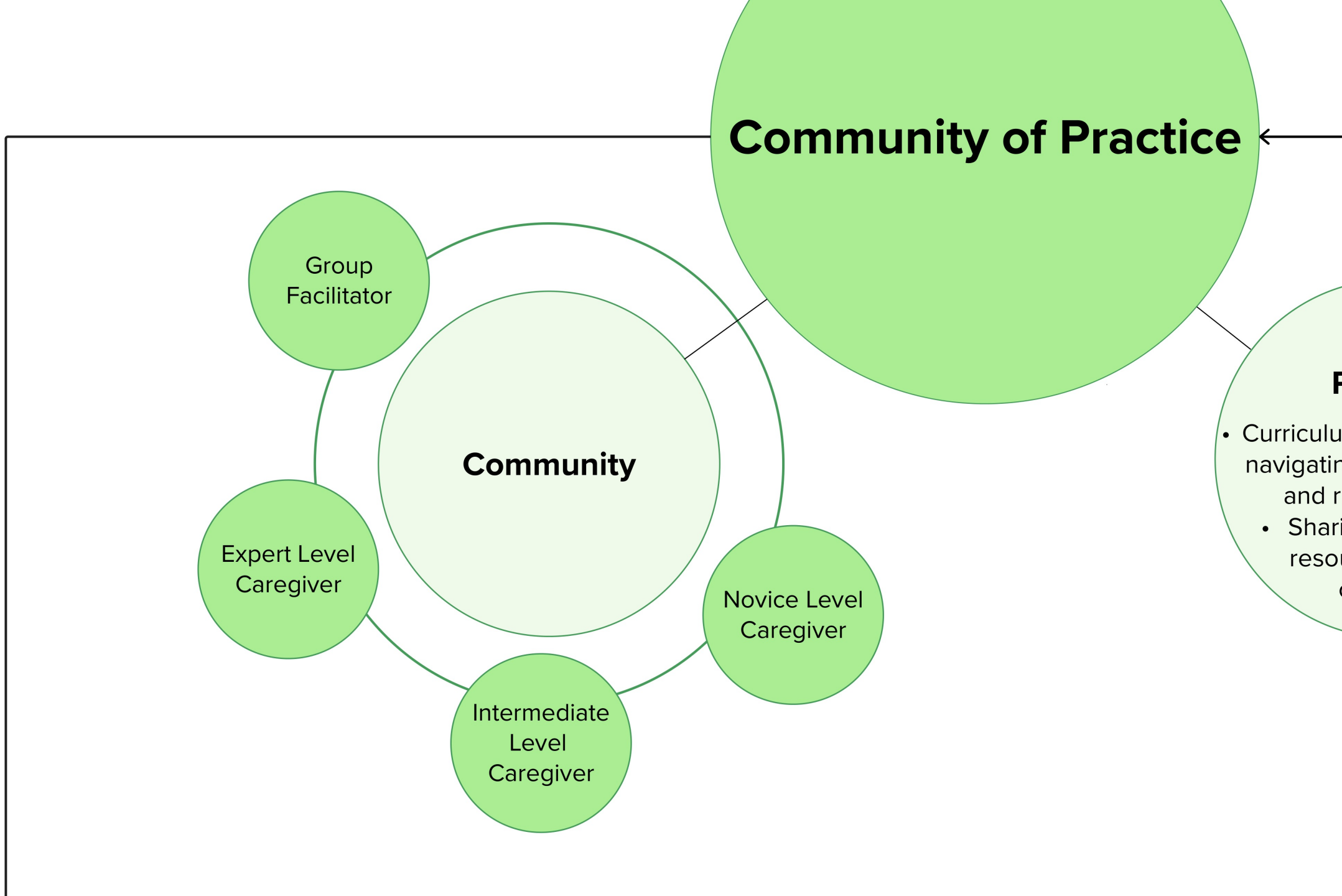


The diagram consists of two circles. The top circle is light green and contains the text 'Domain' and 'Caring for a child with developmental disability'. A vertical line connects the bottom of this circle to the top of a larger, darker green circle below it. The larger circle contains the text 'Community of Practice'. A horizontal line extends from the left side of the larger circle across the page, with an arrowhead pointing to the right at its end.

Domain

Caring for a child with
developmental
disability

Community of Practice ←



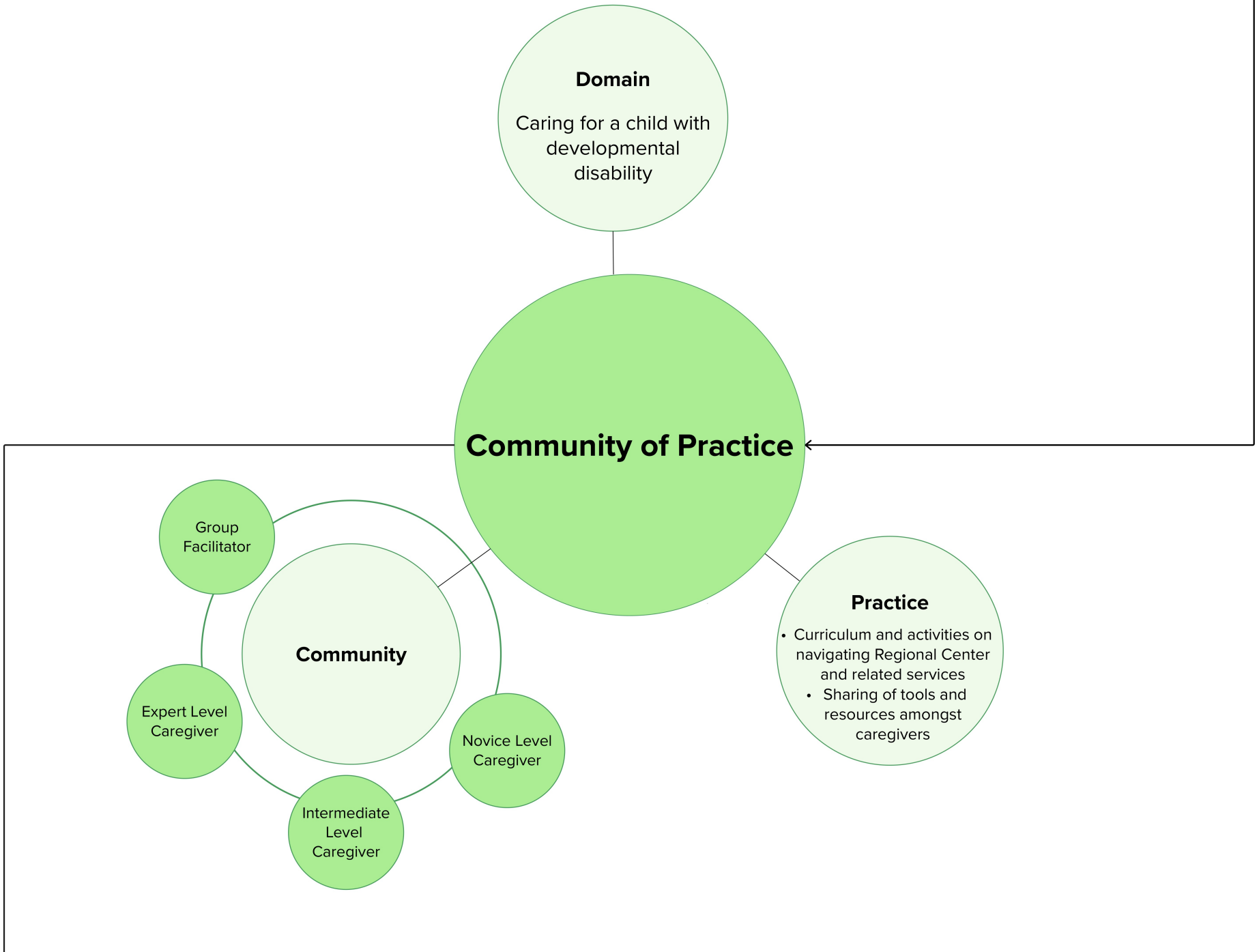
Community of Practice

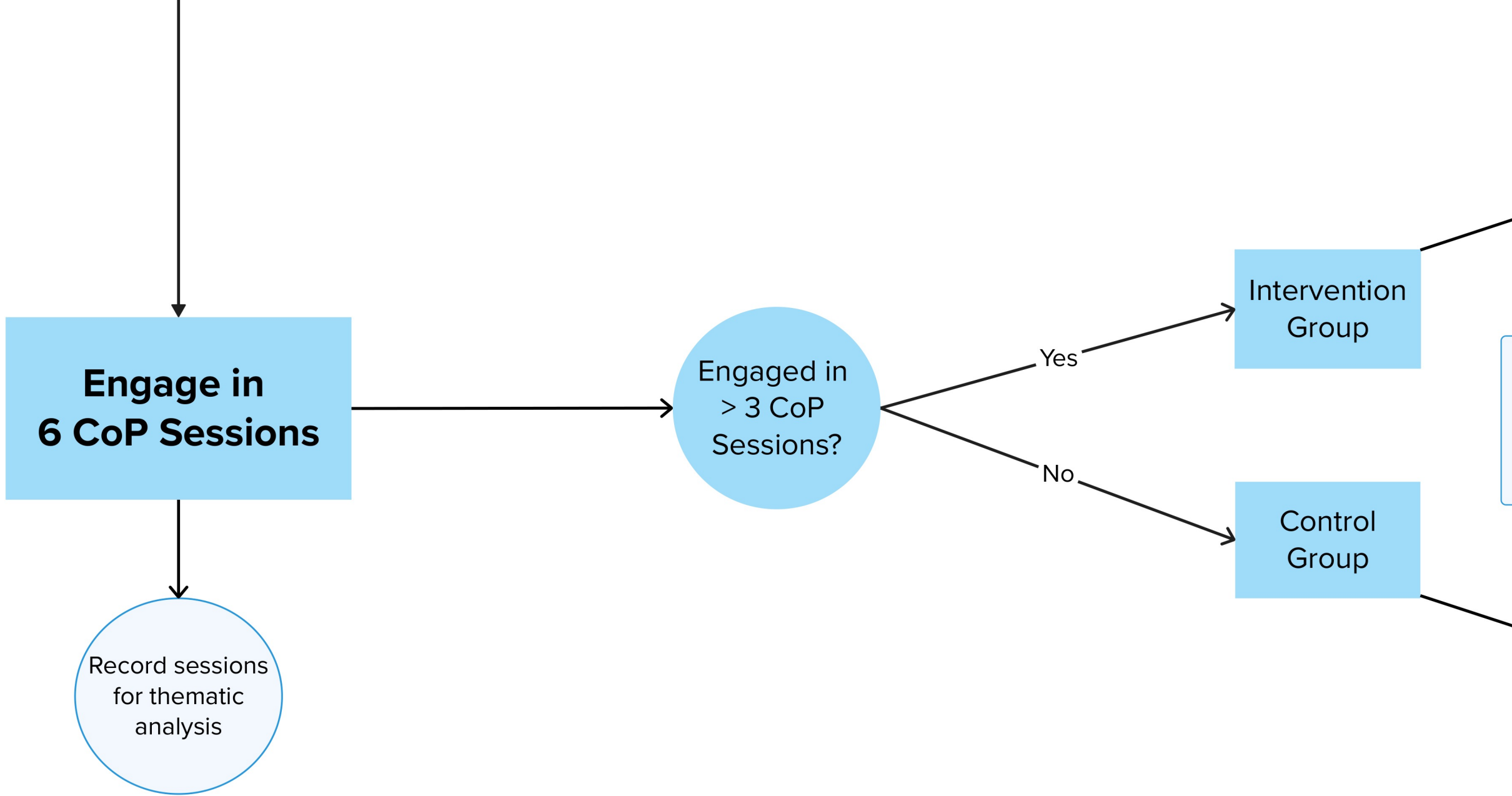
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graph LR; CP((Community of Practice)) --- P((Practice)); CP --- NL((Novice Level Caregiver)); P --- B1[Curriculum and activities on navigating Regional Center and related services]; P --- B2[Sharing of tools and resources amongst caregivers];
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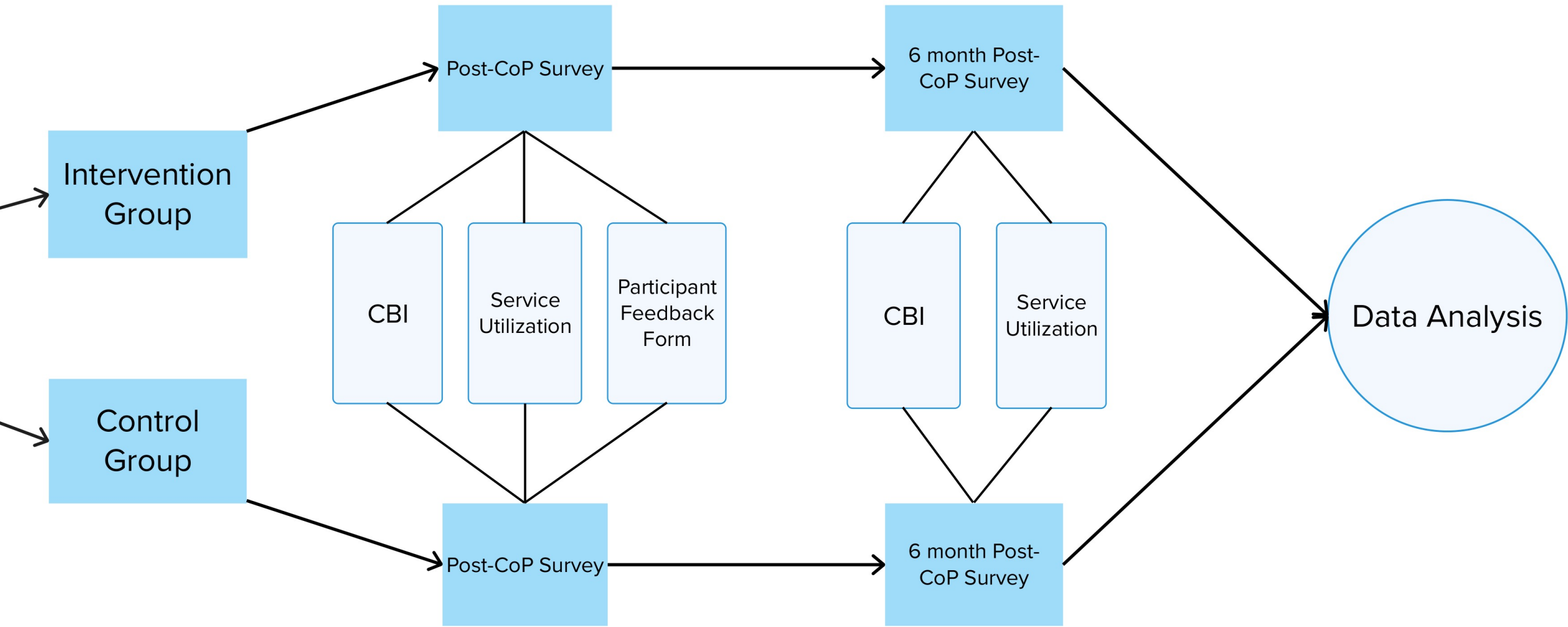
Practice

- Curriculum and activities on navigating Regional Center and related services
- Sharing of tools and resources amongst caregivers

Novice Level
Caregiver

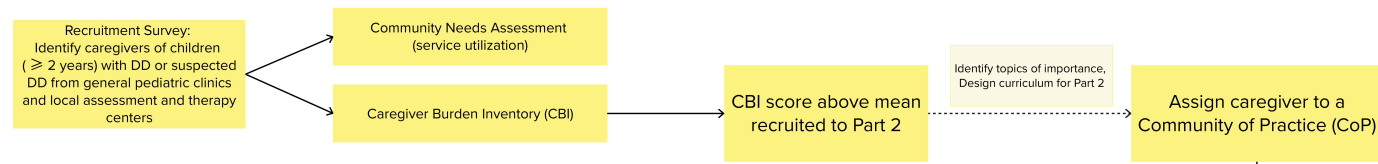






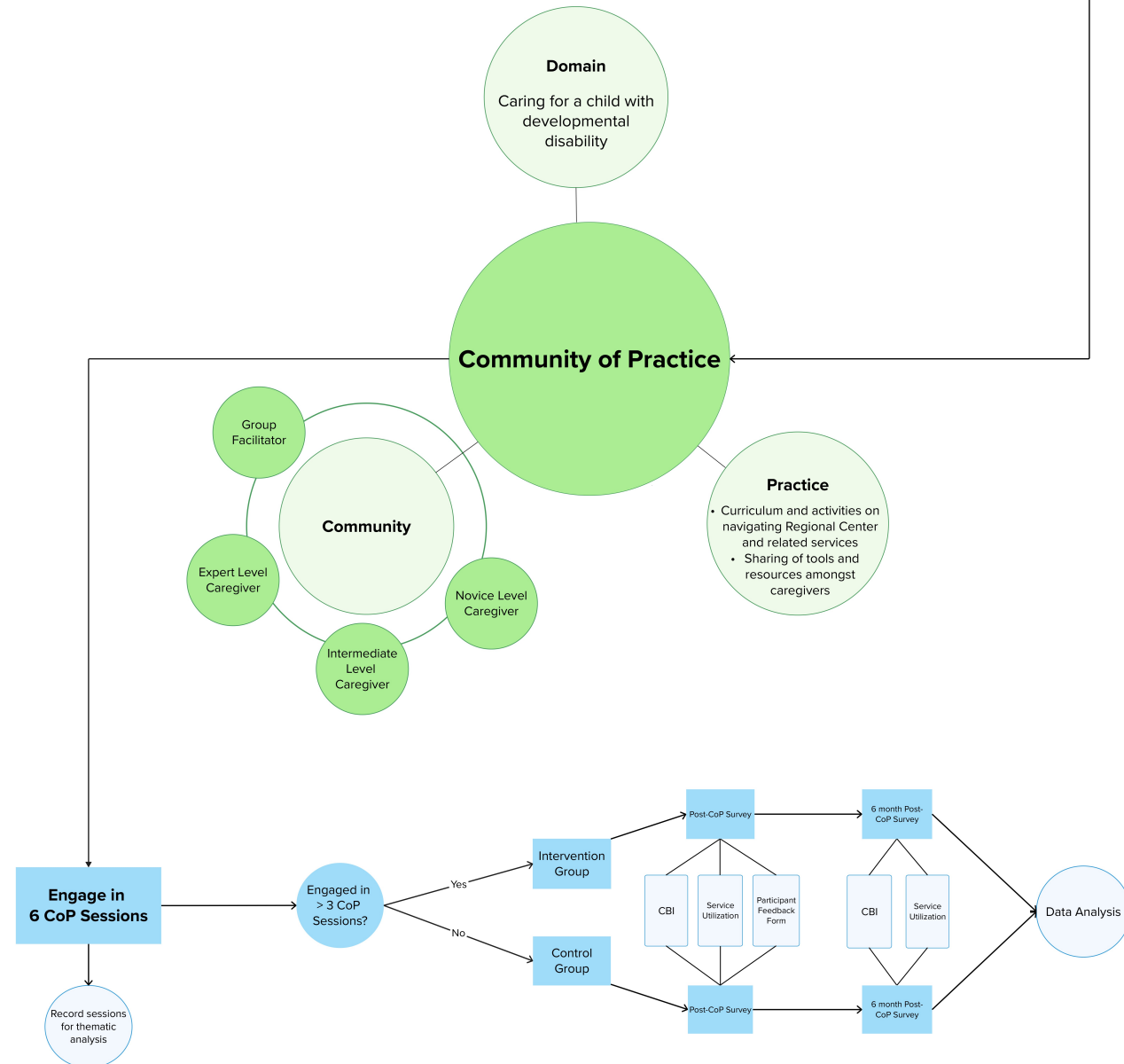
Part 1

Recruitment & Program Design



Part 2

Engage in Intervention



UC RIVERSIDE SCHOOL OF MEDICINE

RESEARCH STUDY OPPORTUNITY NDD CIRCLE

Neuro-Developmental Disorders
Caregiver Inclusion, Resources, Community, Learning & Education

Are you the caregiver of a child who has a neurodevelopmental disorder?

Is your child between the ages of 2-18?

We are conducting a research study for caregivers of children with neurodevelopmental disorders. Participants will be grouped into caregiver circles that meet **online** over Zoom.

Potential Benefits:

- obtain more knowledge about navigating your child's disorder
- learn how to access Regional Center & other services for your child
- gain a new support system with other caregivers

Participation Involves:

Part 1

- Recruitment Survey (10 mins)
scan QR code below

Part 2

- Consent Form
- six 60 min Circle Sessions over Zoom
- Exit Survey (10 mins)
- 6 month Follow Up Survey (10 mins)



You will be compensated for your time!

Scan this code to
get started!



For more information, please
contact our research team
nddcircle@gmail.com
call or text: 909-265-4675

Where are we now?

Now through July 2024: Caregiver Recruitment

Stakeholder Feedback



UC RIVERSIDE SCHOOL OF MEDICINE

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Where are we now?

Stakeholder Feedback

From NDD Community

Physicians and healthcare professionals

Inland Empire NDD collaborative
(group of parents, service providers, educators)

Positively received at AAP NCE

Seeking feedback from AAP CA2

semantic framing of "caregiver burden inventory"

shifting focus from "burden" to caregiver support



Discussion

Intervention anticipated outcomes

- our framework is scalable and can be spread to new contexts
- can address community health inequities

Caregiver-Child dyad anticipated outcomes

- may promote caregiver capacity to advocate for themselves and their child
- may strengthen caregivers' perceived social networks
- may improve Regional Center service access and engagement
- may promote healthier developmental environments for children

Study Limitations

- Sample size
- Self selection
- Self-reported data
- Social desirability bias (CBI)
- Participant attrition

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Feedback Form



Thank You!

