

Creation of **U**niversity-Based **P**rograms
to Improve the Health of **A**dults with
Intellectual **D**isabilities

UP-AID

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The Problem

Adults with Intellectual Disabilities (AID)
have a high incidence of many chronic
health conditions.



Examples of Frequent Chronic Health Conditions in Adults with Intellectual Disabilities

- Psychiatric Disorders/Maladaptive Behaviors.
- Poor Physical Fitness due to sedentary behavior/lack of **meaningful** Physical Exercise.
- Overweight/Obesity
- Metabolic Disorders (e.g., Diabetes, Dyslipidemia)
- Cardiovascular problems (e.g., HBP, diastolic heart failure)
- Low Bone Mineral Density/Osteoporosis/Increased Fracture Risk
- Seizures
- Motor Dysfunction
- Polypharmacy
- Periodontal Disease
- Lack of Etiologic Diagnosis of Neurodevelopmental Disorder/Intellectual Disability
- Poor Outcome from COVID-19

Why do these
*Chronic Health
Conditions often*
remain
inadequately
treated?

- **Lack of training of health professionals** in Medical and Dental Schools: Primary Care and Specialist Physicians and Dentists have little experience with management of health conditions frequently encountered in adults with Intellectual Disabilities.
- **Lack of “Clinical Effectiveness Research”** which addresses treatment of those health conditions that frequently occur in adults with Intellectual Disabilities.
- Therefore, **evidence-based treatments** of those chronic health conditions that frequently occur in adults with Intellectual Disabilities have not been well-established for these medically underserved patients.

How can we begin to correct this Health Disparity ?

Establish a **multidisciplinary** **U**niversity **P**rogram to Improve the Health of **A**dults with **I**ntellectual **D**isabilities (**UP-AID**)

This would include participating faculty from Internal Medicine, Family Medicine, Neurology, Psychiatry, Pediatrics, and the School of Dentistry.

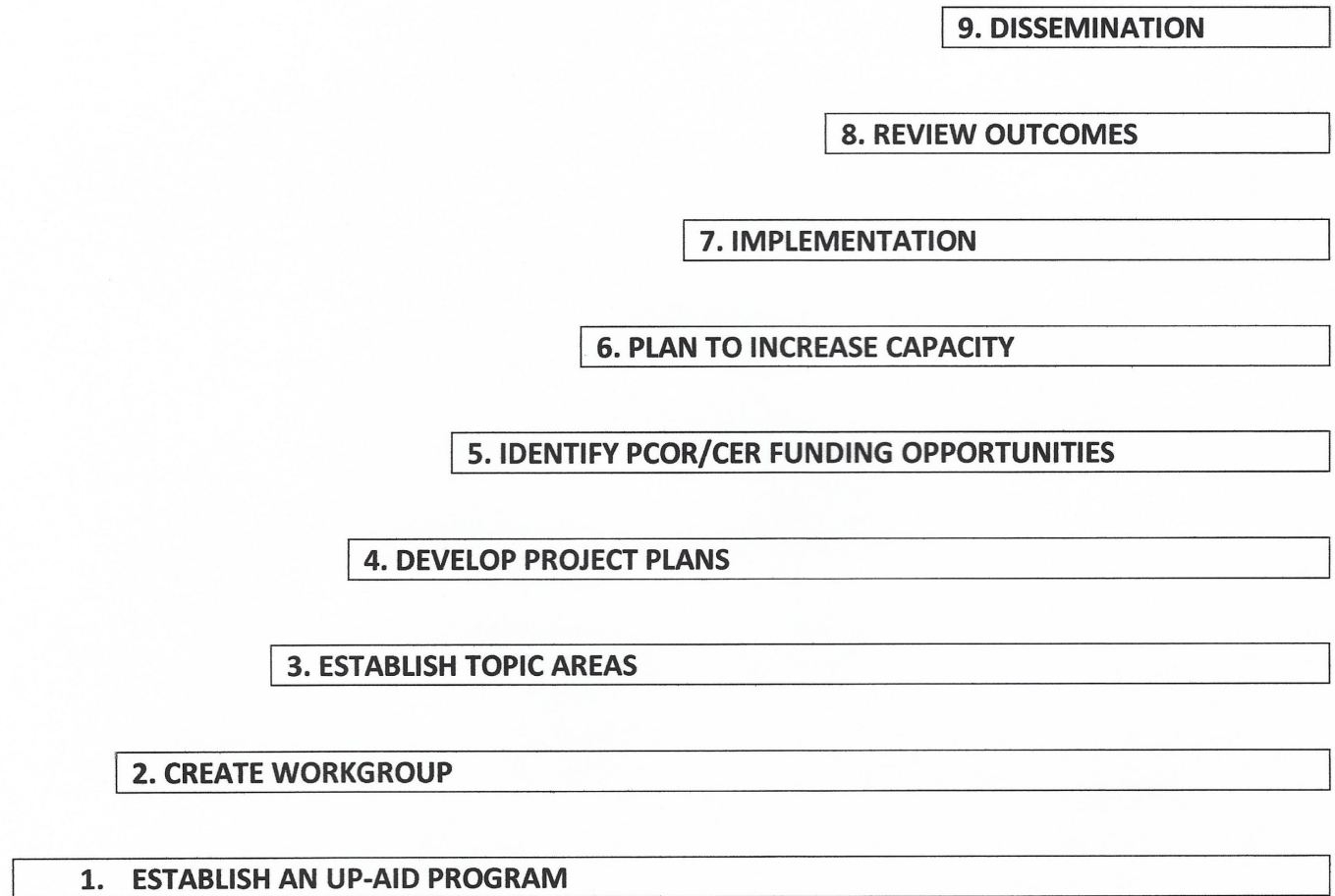
The purpose of this **Program** is to improve the health of adults with Intellectual Disabilities.

Activities of the UP-AID Program

1. To establish teaching programs for Medical/Dental Students
2. To establish teaching programs for Medical/Dental Residents
3. To establish an ACGME approved Fellowship for Physicians and a CODA approved Fellowship for Dentists.
4. To establish Quality Improvement Programs for physicians and dentists
5. To establish basic and general research programs for physicians and dentists.
6. To build the capacity for adults with Intellectual Disabilities to participate in Person Centered Outcomes Research/Clinical Effectiveness Research (PCOR/CER) www.pcori.org

To build the capacity for adults with Intellectual Disabilities to participate in Person Centered Outcomes Research/Clinical Effectiveness Research (PCOR/CER)

**9 Steps to Increase Capacity
for PCOR/Clinical Effectiveness Research
For adults with Intellectual Disabilities**



First order of Business-----

Establish a
“Workgroup”
and then
“Topic”
Selection

- The **Workgroup** consists of a University Research Faculty Member, persons with ID and their caregivers, Advocates, and various Stakeholders (e.g., community physician or dentist)
- This **Workgroup** with **meaningful** leadership from patients and caregivers, begins discussions regarding which health condition should be given priority for research (e.g., lack of physical fitness, obesity, polypharmacy, periodontal disease, etc.)
- A specific **Topic** or Condition is then selected for future Research (e.g., Obesity)

The Project Plan

- A Research Plan or Proposal is then developed following PCORI Guidelines for **Clinical Effectiveness Research (CER)**.
- For example, Two groups of obese patients with ID will be compared; **Group 1** will be treated with a Standard In-Clinic Face-to-Face Behavioral Modification Approach (STANDARD GROUP), while **Group 2** will also receive the STANDARD approach, but in addition will receive a weekly remote telehealth (Zoom) Behavior Modification approach (STANDARD + ZOOM).
- The **Clinical Effectiveness of different approaches** on various outcomes (e.g., weight, A1C levels, periodontal disease, etc) would then be determined in each group (to determine which group approach was more effective).

Identify PCORI Funding Opportunities

- PCORI has awarded **nearly \$3.4 billion in funding** for research studies and related projects
 - PCORI supports **more than 1,900 research studies and related projects**, including those that support the methods and capacity for conducting research.
 - A total of **475 PCORI-funded research studies** are complete with their results posted on the PCORI website.
 - www.pcori.org
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Plan to build “Capacity” for this project is to first establish and then collaborate with UP-AID Programs at other Universities.

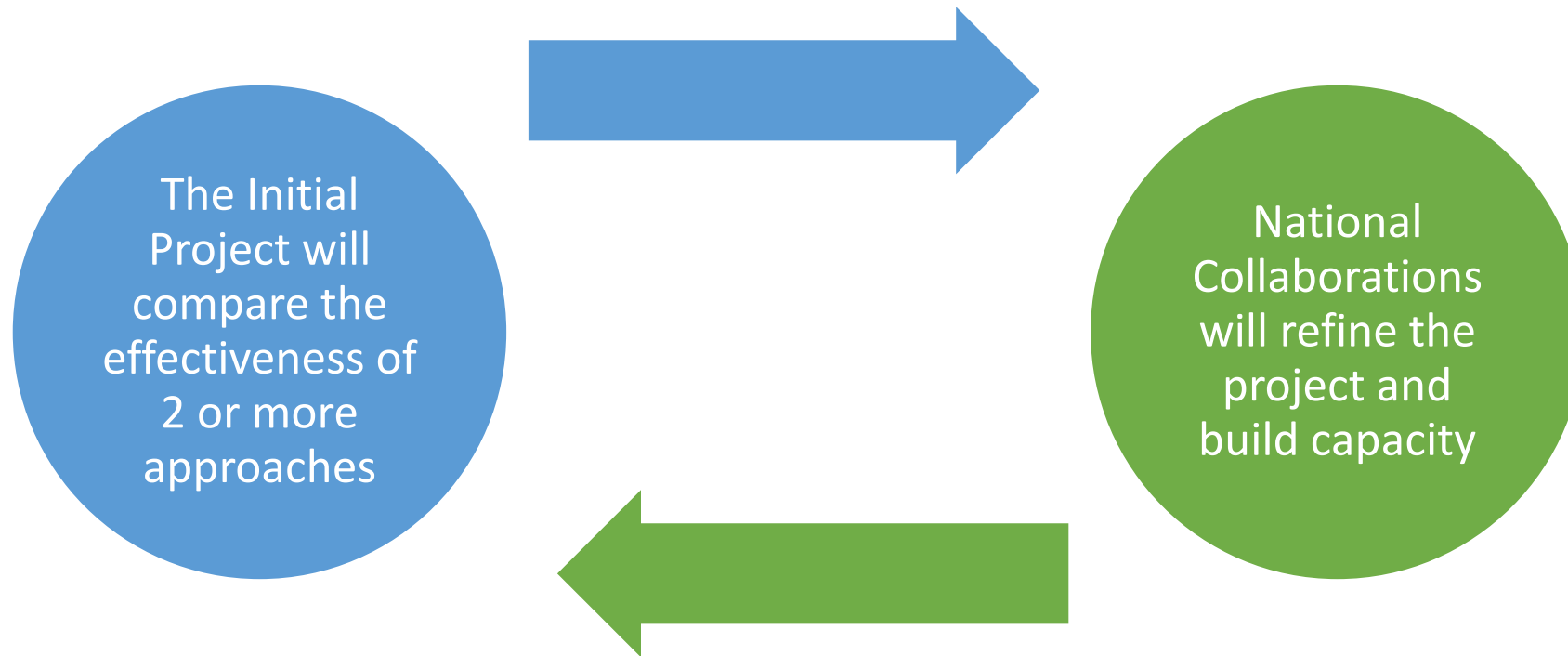
Develop a specific Plan for PCOR/CER research and Identify PCORI Funding Opportunities to support that plan (**Steps1-5**)

Help to establish additional UP-AID Programs in other States that wish to collaborate.

Develop a final Version of the Plan that all sites will use.



Discuss and refine Plan at all UP-AID sites.



Implementation

- **Begin the project at all Sites**
- **Establish collaborative Monthly Zoom Conferences between sites, which will include researchers, patients and caregivers, and other stakeholders.**

Review Outcomes

Outcomes at different sites will be compared and discussed during monthly Zoom Conferences.

Production of a manuscript will begin

Dissemination

All UP-AID Programs will contribute to the Final Product

Lectures

Online Videos

Conferences

Publications

Collaboration with University Health Plans (UHP's)

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