Implementation Works!

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DISCOVERY FOR DISABILITY

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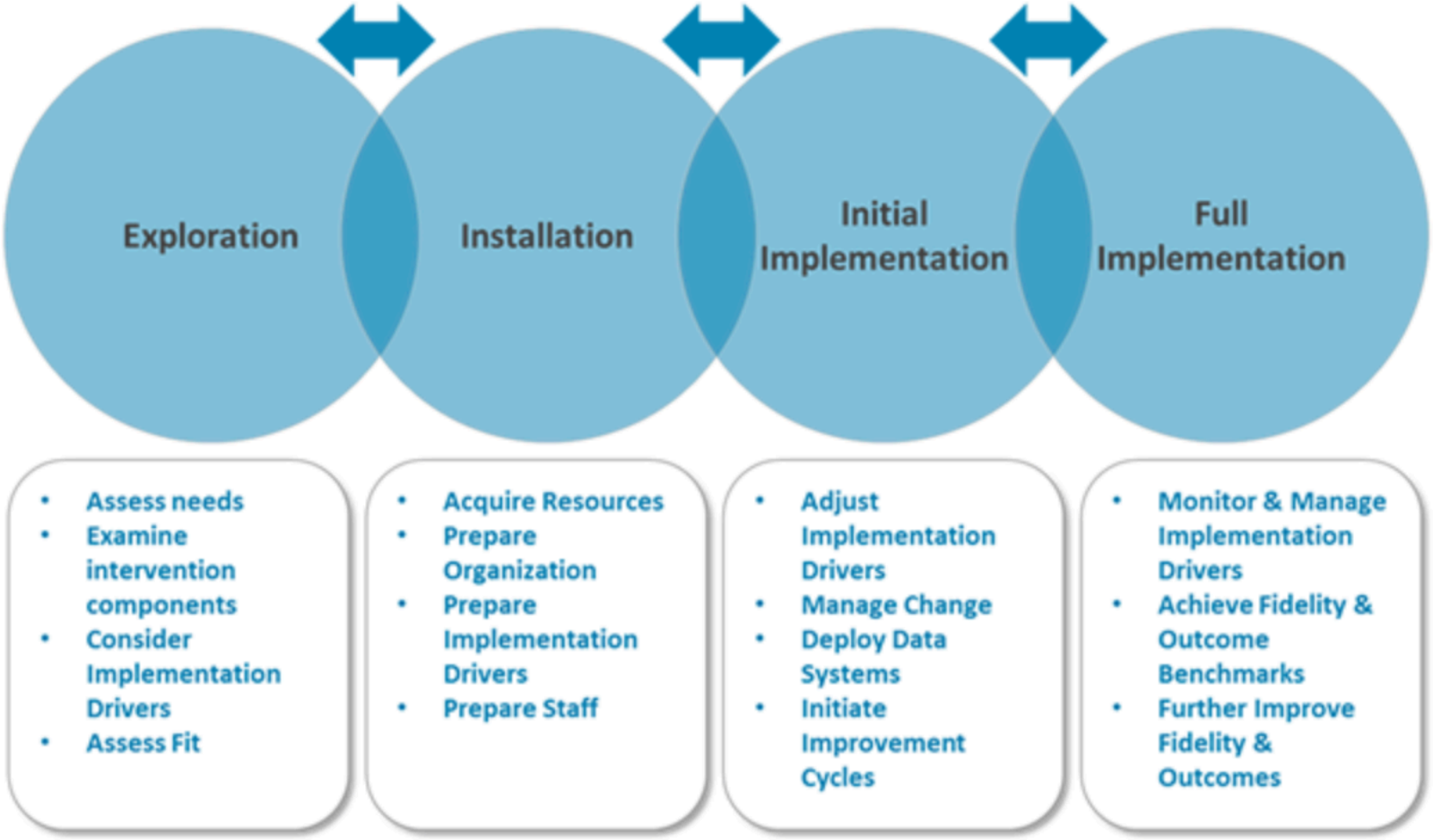
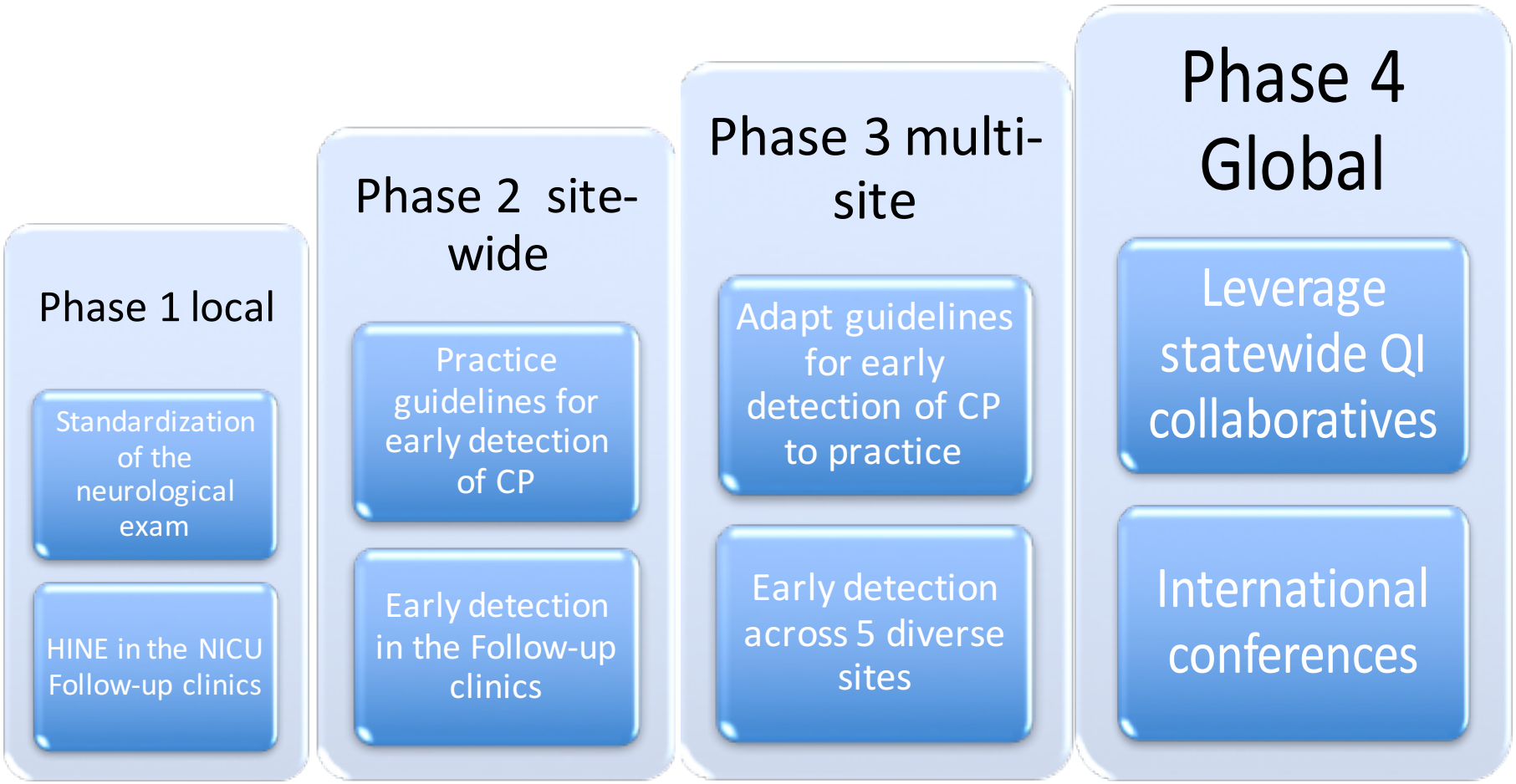
Implementation stages



Scale-up phases



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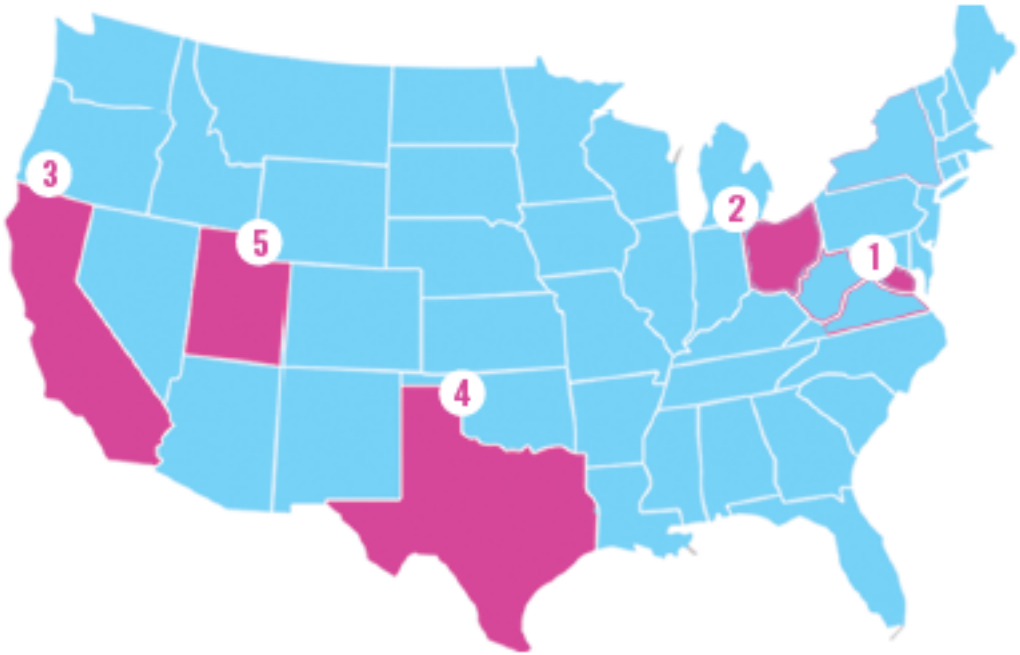
CPF Early Detection Network



CPF NETWORK

1. **Kennedy Krieger Institute**
   Baltimore, MD
2. **Nationwide Children's Hospital**
   Columbus, OH
3. **UCLA Medical Center**
   Los Angeles, CA
4. **University of Texas Health Science Center**
   Houston, TX
5. **University of Utah Medical Center**
   Salt Lake City, UT

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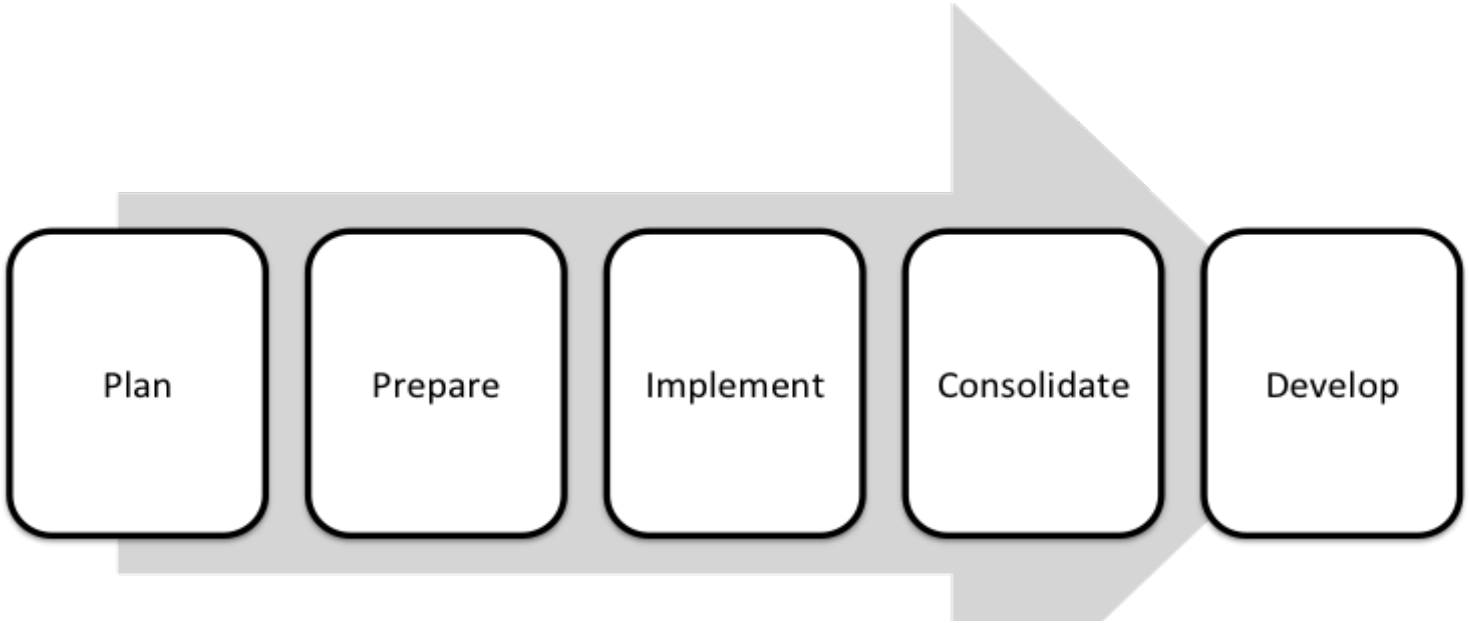
Goals

1. To develop a program to increase the use of proven diagnostic tools and parent counseling and education in follow-up clinics for high-risk infants.
2. Aggregate the learning through multicomponent knowledge translation activities to create a new evidence-based clinical standard of practice.

Specific Aim

Decrease the average at CP diagnosis to 12 months throughout the Implementation Network

Methods



Concept Development
IRB Submissions
Site Visits

Baseline site audit numbers
SWOT analysis
HINE, GMA & TIMP training

Site Visits
Implementation Process Flows
Allocated Staffing

Monthly site and all site meetings→ Cycle of Improvements

Publish
New PDSA cycles
Research

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Site Audit Numbers

- Total visits in clinic ≤12 months of age
- Total visits in clinic at 3-4 months of age
- Individual CP diagnoses in clinic in the 12-month period
- Average age at CP diagnosis in months
- If available, # GMA performed, results, high-risk for CP diagnoses

Parent Surveys

Parents fill out 3 questionnaires 3-6 months after the child's diagnosis of CP is confirmed. Completed in clinic when possible/appropriate or through a link in RedCap. The questionnaires will include:

- Edinburgh Post Natal Depression Scale (standard, published)
- Ways of Coping questionnaire (standard, published)
- Diagnosis visit questionnaire (modified from Baird, 2000)

Current Data (8 months)

	screened in NICU	3-4 mo visits	new CP Dx	# high-risk for CP	Average age at Dx (mo)
Baseline					
Post implementation					

Cramped synchronized GM

MRI performed in response to CS

Absent Fidgety GM

Converted high risk to CP

Projected Data- 12 months

	screened in NICU	3-4 mo visits	high-risk for CP	Age at high risk for CP	new CP Dx	Average age at Dx (mo)
Baseline						
Post implementation						

Specific Site Initiatives

- Houston: Partnership with food bank for access to EDI, expand GMA to high-risk infants
- KKI: Routine neurology consults in the NICU for abnormal GMA
- NCH: QI project to obtain 100% GMA screening in NICU, integrated psychologist follow-up for parent support
- UCLA: restructuring of entire NICU Follow-Up program towards systematic approach
- Utah: HINE ”cheat sheet” for parents; obstacles to neuroimaging after abnormal GMA, expand GMA to high-risk infants

Parent Survey- Receiving the diagnosis before 12 months

A doctor gave the diagnosis
High degree of honesty
High degree of empathy
High degree of support
The information was in a format that I could understand
The doctor allowed me time for questions afterwards
Just right or more than enough information
He/she was sitting down

Parent coping after the diagnosis

Response to early detection
Depression on EDDS*
Concentrated on what I had to do next - the next step
Talked to someone to find out more about the situation
Looked for the silver lining; tried to look on the bright side of things
Felt that time would have made a difference
Hoped for a miracle
Went on as if nothing had happened.
Wished that the situation would go away or somehow be over with
Opportunities for improvement in early detection
Was inspired to do something creative about the problem.
Got professional help
Changed or grew as a person.
Made a plan of action and followed it.
Rediscovered what is important in life

Implementation of Early Detection and Intervention Conference
April 11-13, 2019

Conference Format

- Informational Keynotes and evidence handouts
- SWOT analysis
- Process flow tools
- 49 knowledge translation workshops
- Process building sessions
- Teamwork, connections, food and fun.

8:30-9:15 AM	**KEYNOTE** - Early Intervention for CP: How do we find what works and then, make it happen? (Cathy Morgan, Kath Benfer) STECKER AUDITORIUM						
9:30-10:25 AM	**WORLD CAFÉ** SWOT Analysis ROOMS 025A / 025B / 131 / 137						
10:20-10:45 AM	Break						
10:45-11:35 AM	Pharma Interventions, Orthotics & Standers ROOM 131	Vision: Assessment & Interventions ROOM 025B	Motor Interventions ROOM 025A	Speech & Language Interventions ROOM 040	Enhancing Family Participation ROOM 137	Nutrition Considerations & Practices ROOM 138	Parent Well-being, Positive Parenting, & Mindfulness ROOM 054
11:40-12:30 PM	Optimizing Sleep and Mitigating Pain ROOM 131	Cognition: Interventions ROOM 025B	Motor Interventions ROOM 025A	Speech & Language Interventions ROOM 040	Feeding Evaluation & Intervention ROOM 137	Pharma Interventions, orthotics & standers ROOM 138	Parent Well-being, Positive Parenting, & Mindfulness ROOM 054
12:30-1:00 PM	LUNCH						
1:00-1:50 PM	Feeding Evaluation and Intervention ROOM 131	Vision: Assessment & Interventions ROOM 025B	Motor Interventions ROOM 025A	Speech and Language Interventions ROOM 040	Enhancing Family Participation ROOM 137	Nutrition Considerations & Practices ROOM 138	Optimizing Sleep and Mitigating Pain in Infants ROOM 054
1:55-2:45 PM	Optimizing Sleep and Mitigating Pain in Infants ROOM 131	Cognition: Interventions ROOM 025B	Motor Interventions ROOM 025A	Parent Well-being, Positive Parenting, & Mindfulness ROOM 040	Feeding Evaluation & Intervention ROOM 137	Nutrition Considerations & Practices ROOM 138	Pharma Interventions, Orthotics & Standers ROOM 054
2:45-3:15 PM	Break						
3:15-4:30 PM	**WORLD CAFÉ** Final Process Design ROOMS 025A / 025B / 131 / 137						

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Save the Date
April 11, 12 & 13, 2019

Implementation of Early Detection and Intervetion for Cerebral Palsy Conference

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Nationwide Children's Hospital
700 Columbus Drive
Columbus, OH 43205

yourcpf.org/early-detection-conference/ - 3 Columbus Circle - 15th Floor - New York, NY - 10019

For more information please contact Rebecca Lam at rebecca.lam@yourcpf.org

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