

# The Journey for a Cerebral Palsy Diagnosis: A Family Experience Survey



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## Why does this matter?

- The Cerebral Palsy Early Diagnosis Clinic (CPEDC) is exploring how families feel about the diagnosis process
- Data collected will help make changes within the CPEDC so it can be more family-centred and meet the needs of parents and caregivers

## What did we do?

- We created a survey for the families of children diagnosed with CP in the last 5 years from the CPEDC or other clinics
- Questions address several aspects of the diagnosis process, highlighting what respondents feel was done well or was lacking
- We conducted follow-up interviews for more details to identify areas of success and potential improvement

## Survey Responses

*"They were amazing and made us feel like there was hope and our child was thriving. They were very kind."*

-CPEDC participant

*"Have Sunnyhill involved early with all children or have more "Sunnyhill" clinics around BC. Our whole province is not as solid and it's sad not all children can access Sunnyhill."*

-CPEDC participant

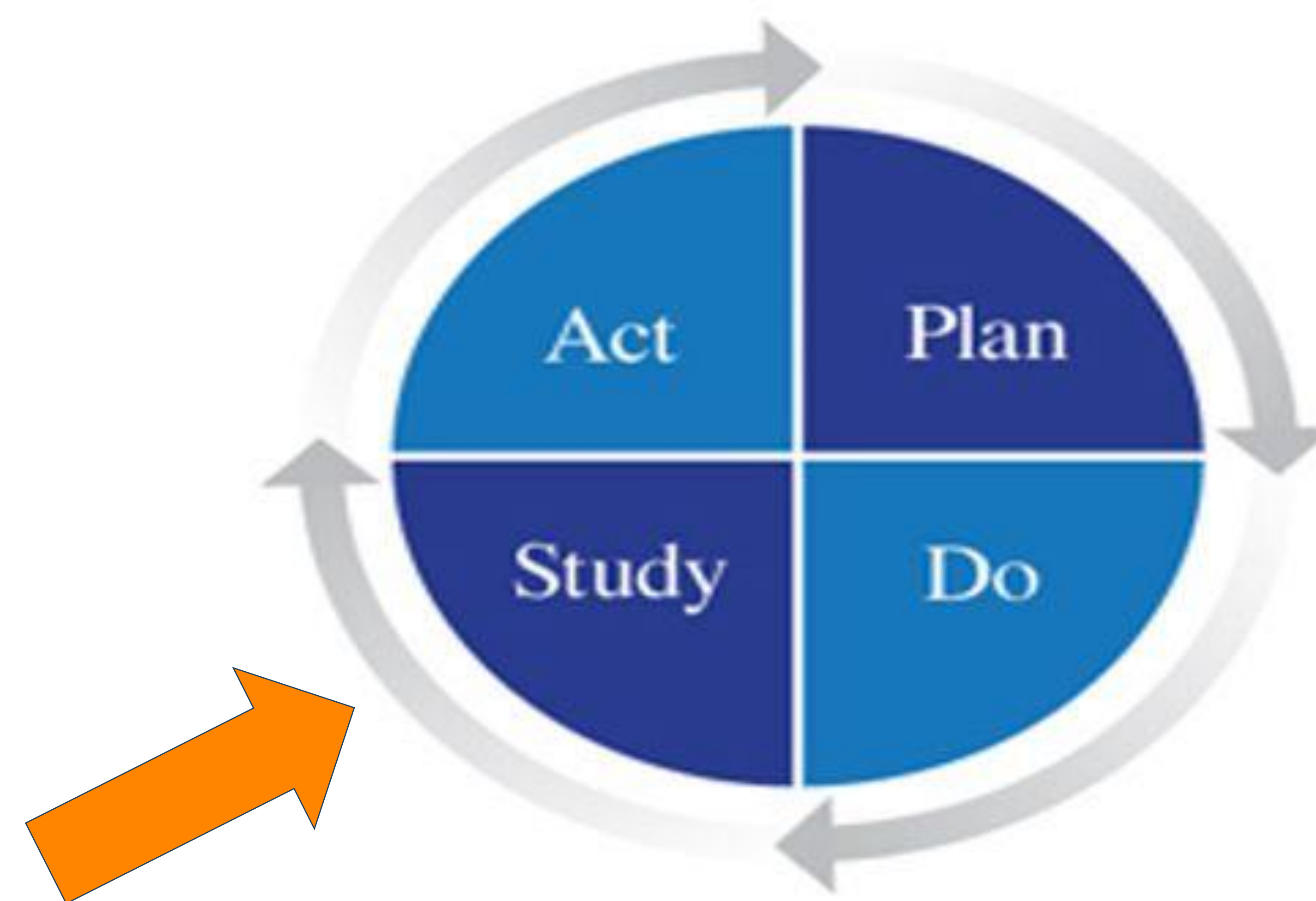
*"...mental health support FOR FATHER. I had [support] postpartum, which ended after 1 year postpartum. We both needed several years of support."*

-other clinics participant

*"...it's just one of those things where it's like is [the diagnosis] 100%? We don't really know...had they made the diagnosis our first visit to neonatal follow-up? I mean, honestly, I don't know."*

-other clinics participant

## The CP Early Diagnosis Clinic – A Quality Improvement Model



## What we learned.

- Key successes of the CPEDC include kind and compassionate care providers, useful information provided in digestible amounts, a straightforward process, and timely diagnosis
- Areas for improvement to the CPEDC include increased access to its services, guidance regarding therapeutic options and how to access them, a more personalized approach to each patient, and mental health support for parents/caregivers throughout and beyond the diagnosis process

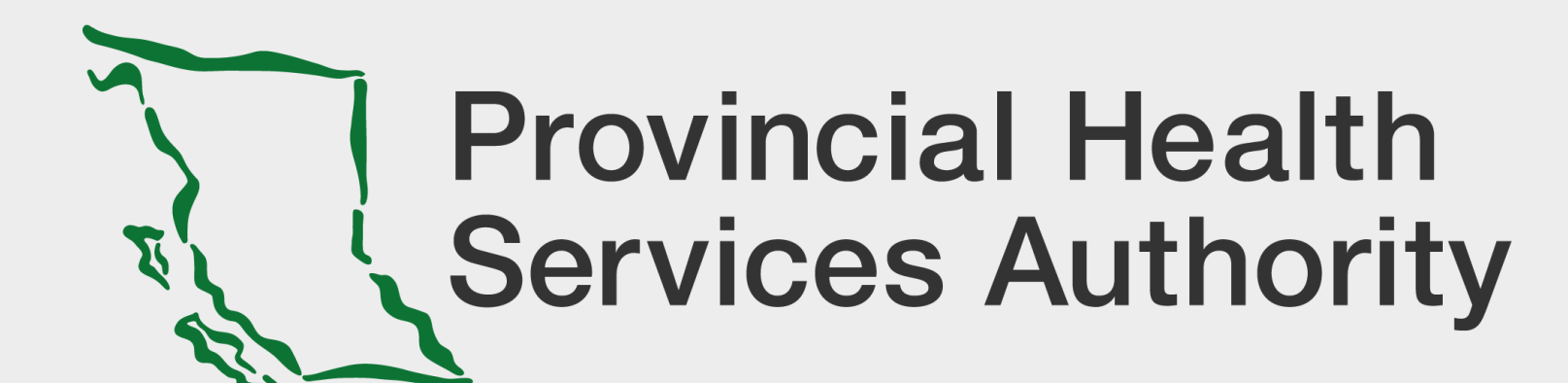
✓ The focus of this iteration of the PDSA cycle is to gather information. We want to hear from parents and caregivers about their diagnosis experiences.

✓ In the next PDSA cycle we aim to implement changes in the clinic that will improve the diagnosis experience for parents and caregivers.

Sunny Hill Health Centre



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