

Supplementary Table S1: Respondent experiences regarding age of diagnosis in Maryland and Delaware

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| Delayed diagnosis common (n = 15) | |
| Too late, Doctor reluctance, Wait and see approach | We wait too long! ID50 |
| | It is often diagnosed much later than it should be ID45 |
| | diagnosis could be earlier, MDs often hesitant to label too quickly, it seems ID56 |
| | The doctors tend to be reluctant to diagnose CP early and usually will say "let's wait and see" ID7 |
| Some diagnosed early (n = 4) | |
| | Some babies are diagnosed w/CP younger than 7 months ID45 |
| | Early detection recommended as would also select 0-6 months above as well ID20 |
| Age of diagnosis influenced by severity (n = 3) | |
| Timing of diagnosis | depends upon the severity. there are kids who suspect at 0-6m given their presentation and history and may receive a diagnosis that early or 7-12 mo, but more often it is not until kids are not walking by age expected milestone ID 31 |
| | They either get a CP dx at birth or it will not be until 18+ months, usually between 18 and 30 months ID 29 |
| | milder cases of diplegia or hemipares, often is delayed to 25 - 36+months ID 92 |
| System factors: Referral and health pathways (n = 20) | |
| Diagnostic test limitations | Usually hear the doctors do not want to do testing (that may or may not involve sedation) until 2 years of age ID32 |
| Referral delays | delays in or barriers to getting genetic testing or getting sedated MRI may contribute to perceived delayed diagnosis ID53 |
| Specialty clinics versus community | I think our specialty clinics do a good job of diagnosing CP early. I think there are many patients in the community that come to us later without having been given a Dx ID61 |
| Challenges | It is more challenging to get a diagnosis of CP now compared to 20 years ago ID80 |
| Social factors: Family perceptions and attitudes (n = 5) | |
| Family impact of delay | The longer diagnosis is deferred, the more difficult for parents and family ID49 |
| Family acceptance/readiness | diagnosis sometimes takes a while due to other health issues, difficulty accepting that CP may be present by the family, and wanting to rule out other possible explanations first. ID73 |
| | working on improving - balancing goal of early diagnosis with individual family need/readiness (without limiting therapies/support) ID34 |
| Parent, provider driven | Feels children are being treated to address deficits but not getting a formal diagnosis until later unless parents or providers push for a diagnosis ID6 |
| Health provider knowledge and perceptions (n = 12) | |
| Lack of multidisciplinary working Resistance to change Lack of knowledge | I wish MDs would identify earlier and trust providers ... stop recommending more of the same therapy and identify resources ID41 |
| | Yes it is too late in coming when we see signs early enough to discuss much sooner than the pediatrician is willing to ID5 |
| | I find that I'm frequently the first professional to discover that they probably have CP. ID95 |
| Early 'at risk' diagnosis | I like to diagnose or at least educate families on the possible diagnosis of CP so they can get the correct services in place ID37 |
| Health provider perceptions/bias | "CP" is such a broad swatch. For the mildest i tend to use another label in medical communications because of the potential for mis-interpretation of its impact on functioning ID48 |