



DEC Position Statement on LBW and Prematurity and State Part C Eligibility

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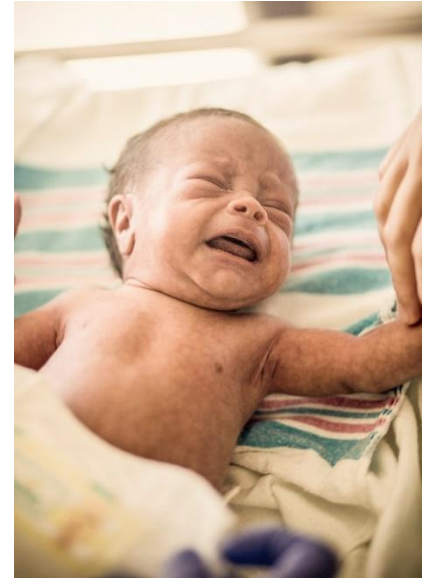
Agenda

- Background: LBW and prematurity
- DEC position statement on LBW and prematurity
- State early intervention (Part C) eligibility policies
- How LBW and prematurity used for eligibility
- State data on LBW and prematurity eligibility
- Discussion and questions



LBW Terminology

- LBW = < 2500 grams or 5.5 pounds (about 10% of population)
 - very low birth weight (VLBW) = < 1500 grams
 - extremely low birth weight (ELBW) = < 1000 grams
- Preterm birth is defined as < 37 weeks gestation of a 40-week pregnancy
 - moderate to late preterm = 32 to < 37 gestational weeks
 - very preterm = 28 to < 32 gestational weeks
 - extremely preterm = < 28 weeks



What does the literature say about LBW?

- We are able to keep smaller and smaller and earlier gestation infants alive.
- Many LBW infants spend 2-6 weeks in NICU.
- Parents experience stress and uncertainty and need support during the transition home.



What does the literature say about LBW? (continued)

- Medical and health conditions occur in first year of life and can continue to later ages.
- Many LBW infants show early difficulties with:
 - motor development including oral-motor difficulties,
 - language acquisition, processing, and communication,
 - engagement (e.g., exploration, initiative),
 - emotional regulation (e.g., persistence, frustration, competence),
 - social-emotional competence (e.g., joint attention, imitation/play, empathy, prosocial behaviors).

Conclusions about LBW Eligibility

- There is abundant evidence that this is a population at high risk for poor outcomes and the origins of their poor outcomes begin prenatally and in infancy.
- The costs of the poor health, learning, behaviors, school achievement, and long-term life outcomes of LBW and/or preterm are substantial.
- These data support identifying and providing EI services early on to reduce the long-term costs and poor outcomes.

Position Statement on Low Birth Weight, Prematurity & Early Intervention



DEC Position Statement Process

- Developed by a workgroup made up of DEC members representing faculty, researchers, and EI technical assistance consultants who
 - reviewed the literature on LBW and EI,
 - investigated state criteria for eligibility, and
 - determined the need for a position statement.
- Included multiple levels of review and revisions within DEC.
- Finalized and approved by the DEC Executive Office.
- Released in September 2018 ([DEC link](#)).

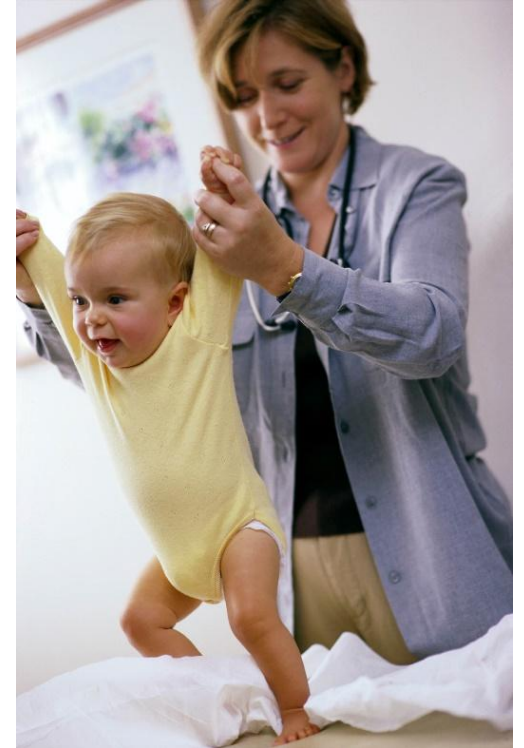
DEC Recommendations

- DEC recommends that LBW and/or preterm diagnoses should be considered diagnosed physical or mental condition that have a high probability of developmental delay to automatically make an infant eligible to receive EI services.
 - There is no need to wait to provide EI services until full blown delays and functional deficits are present.



DEC Recommendations (continued)

- Across the range of LBW, there is strong research evidence to support the contention that all LBW infants born < 1500 grams are at high risk for delays, and this weight should be used as the national standard for automatic EI eligibility.
- In addition, children born < 37 weeks should be considered for EI services.



DEC Call for Action for States

- DEC supports setting a national standard of LBW < 1500 grams and < 37 weeks for EI eligibility.
- DEC supports LBW and prematurity as a national recommendation for EI eligibility, with each state responsible for defining specific criteria such as birthweight and/or maximum gestational age (e.g., < 37 weeks) for which LBW can be used as criteria for EI eligibility.
- DEC encourages each state to review its eligibility policy and consider how their current eligibility criteria align with the current research.

Part C definition of “infant or toddler with a disability” includes developmental delay.

Experiencing a *Developmental Delay*, as measured by appropriate diagnostic instruments and procedures, by qualified personnel who must use *informed clinical opinion*, in one or more of the following areas:

- Cognitive development
- Physical development, including vision and hearing
- Communication development
- Social or emotional development
- Adaptive development



All states define developmental delay, but criteria vary from state to state.

Criteria	Number of states*
2 standard deviations below the mean in one area	19
1.5 standard deviations below the mean in two or more areas	19
25% or greater delay in one or more areas	18
Other delay criteria	14
30-40% delay in one area	13
25% or greater delay in two or more areas	11
1.5 standard deviations below the mean in one or more areas	10
Atypical development mentioned	8
50% delay in one or more areas	7
Criteria differ by domain and/or diagnosis ¹	3
Any delay	2

¹ Language delays and deaf or hard of hearing

* States can have multiple criteria in their developmental delay definition so list sums to more than 57 (the total number of states and territories)

Part C eligibility includes diagnosed conditions; regulations do not mention LBW/prematurity, but some states include them.

Diagnosed physical or mental condition that has a high probability of resulting in developmental delay includes conditions such as:

- chromosomal abnormalities;
- genetic or congenital disorders;
- sensory impairments;
- inborn errors of metabolism;
- disorders reflecting disturbance of the development of the nervous system;
- congenital infections;
- severe attachment disorders; and
- disorders secondary to exposure to toxic substances, including fetal alcohol syndrome



Informed clinical opinion may be used to establish eligibility for children with LBW.

“Qualified personnel must use informed clinical opinion when conducting an evaluation and assessment of the child. In addition, the lead agency must ensure that informed clinical opinion may be used as an independent basis to establish a child’s eligibility under this part even when other instruments do not establish eligibility; however, in no event may informed clinical opinion be used to negate the results of evaluation instruments used to establish eligibility under paragraph (b) of this section.”

- NECTAC Notes 28 Informed Clinical Opinion:
<https://ectacenter.org/~pdfs/pubs/nnotes28.pdf>
- DEC Recommended Practices Checklist on Informed Clinical Reasoning:
https://ectacenter.org/~pdfs/decrp/ASM-1_Informed_Clinical_Reasoning_2018.pdf

Regulatory language includes LBW for those states that serve at-risk infants and toddlers.

An infant or toddler who is at risk of experiencing developmental delays because of biological or environmental factors that can be identified including:

- **low birth weight**
- respiratory distress as a newborn
- lack of oxygen
- brain hemorrhage
- infection
- nutritional deprivation
- a history of abuse or neglect and
- being directly affected by illegal substance abuse or withdrawal symptoms resulting from prenatal drug exposure)



Very few states serve infants and toddlers at risk.

Eight out of 57 states/jurisdictions define and serve at risk:

- Number of required at-risk factors range from 1 to 5
- All eight include biological or medical risk factors
- Five of the eight include environmental risk factors



Example of state data from eligibility database.



California

Part C Developmental Delay Eligibility Criteria

33% or greater delay in one or more developmental areas

At-Risk Served Under Federal Part C Policies

Yes

High risk for a developmental disability exists when a multidisciplinary team determines that an infant or toddler has a combination of two or more risk factors which include:

- Prematurity of <32 weeks gestation and/or LBW of <1500 g
- Small for gestational age: below the third percentile on the National Center for Health Statistics growth charts
- Prenatal substance exposure, positive infant neonatal toxicology screen or symptomatic neonatal toxicity or withdrawal

See link for full list of high risk factors.

State Part C Eligibility Policy

[California Part C Eligibility Policy](#)

Additional Links

[Additional Eligibility Information](#)

Selected Categories of Diagnosed Conditions

Hearing Impairment

An established risk condition exists when an infant or toddler has a solely

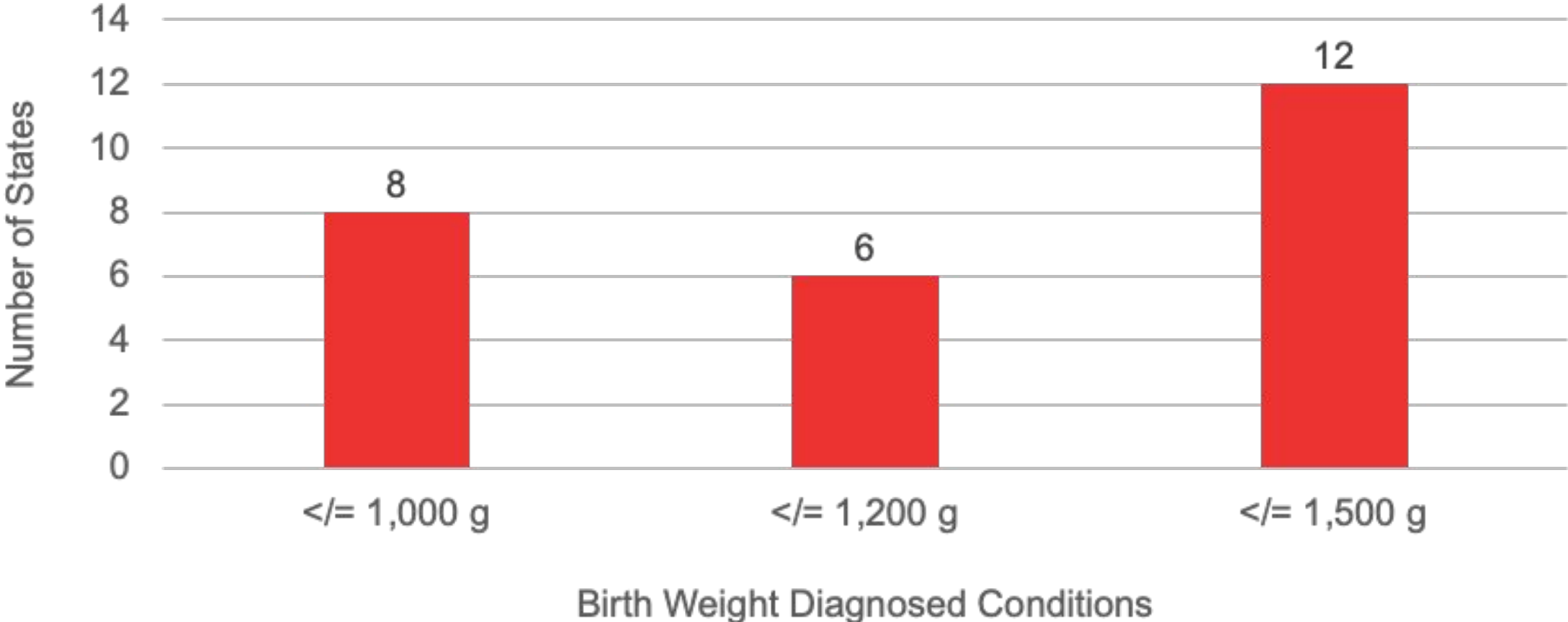
Findings about states that include LBW as a diagnosed condition.

26 states include LBW as a diagnosed condition:

- Eligible birth weight varies from $\leq 1,000$ grams to $\leq 1,500$ grams
- In some states, infants born LBW are only eligible for EI if they also meet other criteria; for example:
 - An additional condition such as APGAR of 6 or less at 5 minutes
 - A “complication” such as intraventricular hemorrhage or bronchopulmonary dysplasia



Birth weights included as diagnosed conditions and the number of states that use each birth weight.



State diagnosed conditions around LBW only include VLBW and ELBW.

- DEC position statement recommends serving children < 1,500 g
- Of the 26 states that include birth weight in their diagnosed conditions, more than half do not meet this recommendation

Birth Weight Categories

Low birth weight (LBW)

Birth weight < 2,500 g

Very Low Birth Weight (VLBW)

Birth weight < 1,500 g

Extremely Low Birth Weight (ELBW)

Birth weight < 1,000 g

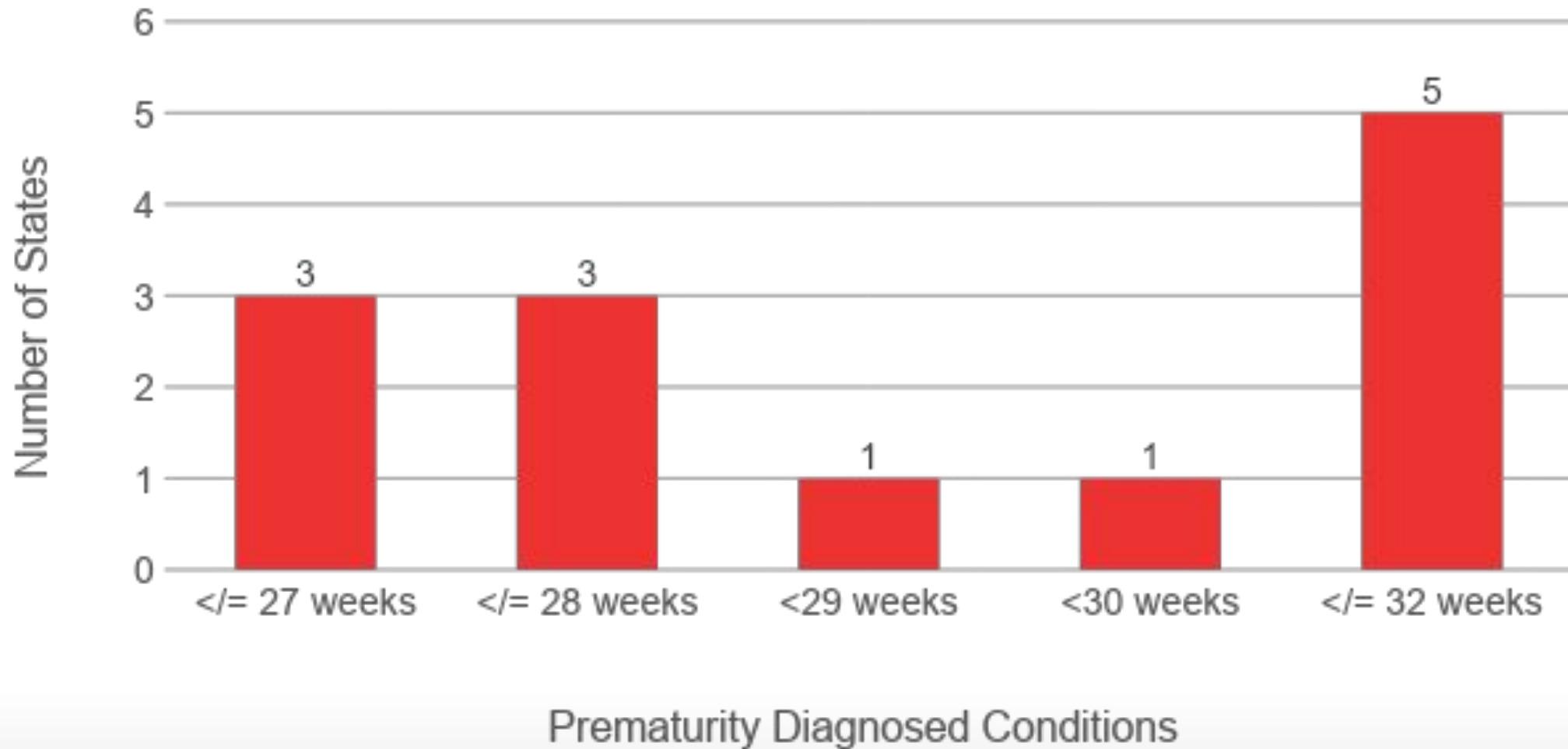
Findings about states that include prematurity as a diagnosed condition.

13 states specifically mention prematurity (gestational age – GA)



- Weeks of prematurity varies from < 27 weeks to 32 weeks
- In some states infants born later are eligible if they also meet other criteria; for example:
 - State A: < 30 weeks GA or 30–36 weeks GA with at least one other criteria, e.g., IUGR less than 10th percentile
 - State B: \leq 32 weeks GA or < 36 weeks GA with significant environmental risk (1 or more factors)

Prematurity levels (in weeks GA) included as diagnosed conditions and the number of states that use each.



State diagnosed conditions around prematurity include moderate to late preterm, very preterm, and extremely preterm categories.

- DEC position statement recommends children born < 37 weeks be considered for EI services

Gestational Age Categories

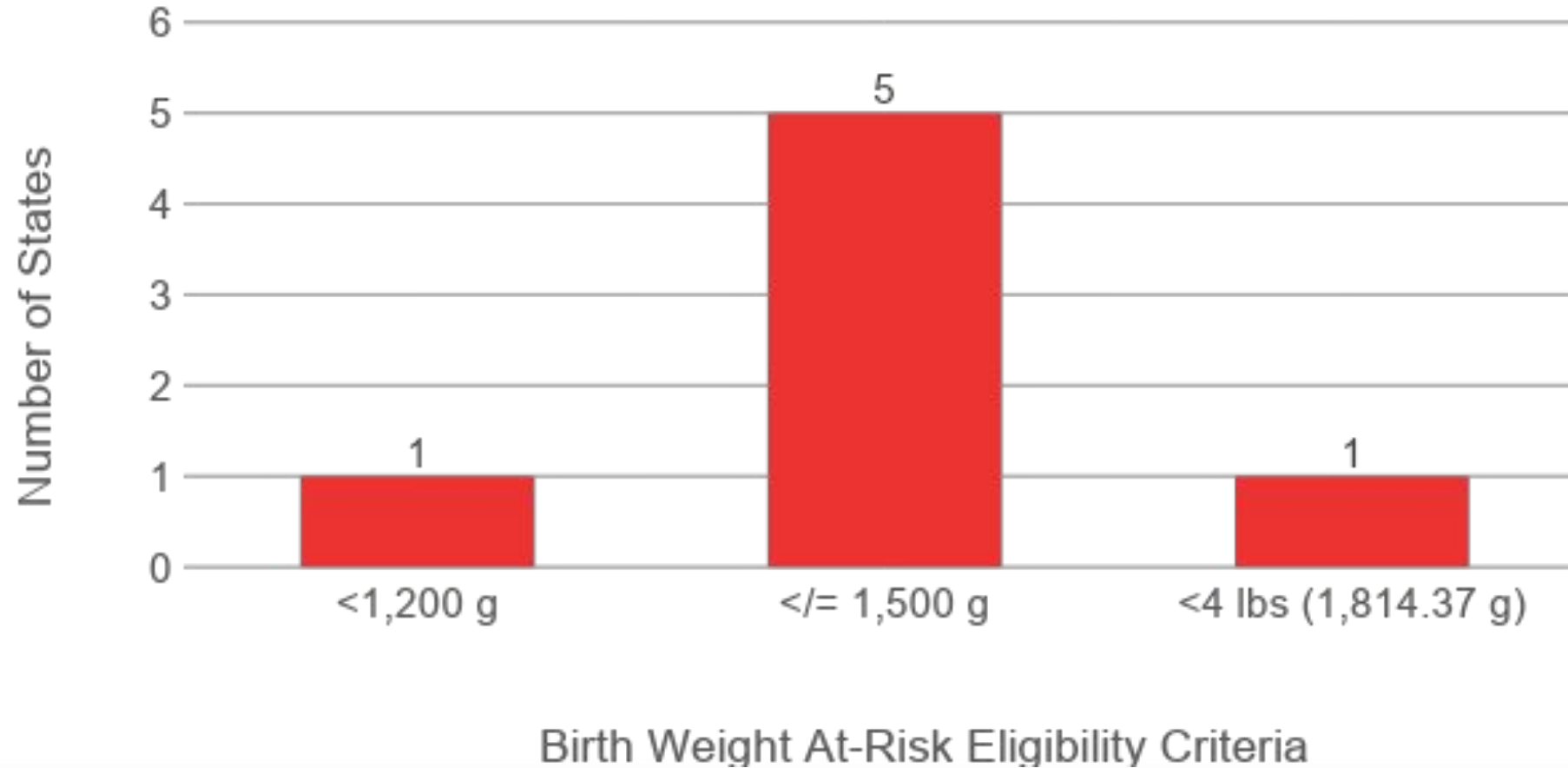
Preterm	Birth before 37 weeks of pregnancy
Moderate to late preterm	Birth between 32 - 37 weeks
Very preterm	Birth between 28 - 31 weeks
Extremely preterm	Birth < 28 weeks
Periviable	Birth between 22 - 24 weeks

Most states that serve infants and toddlers at-risk include LBW and prematurity as risk factors.

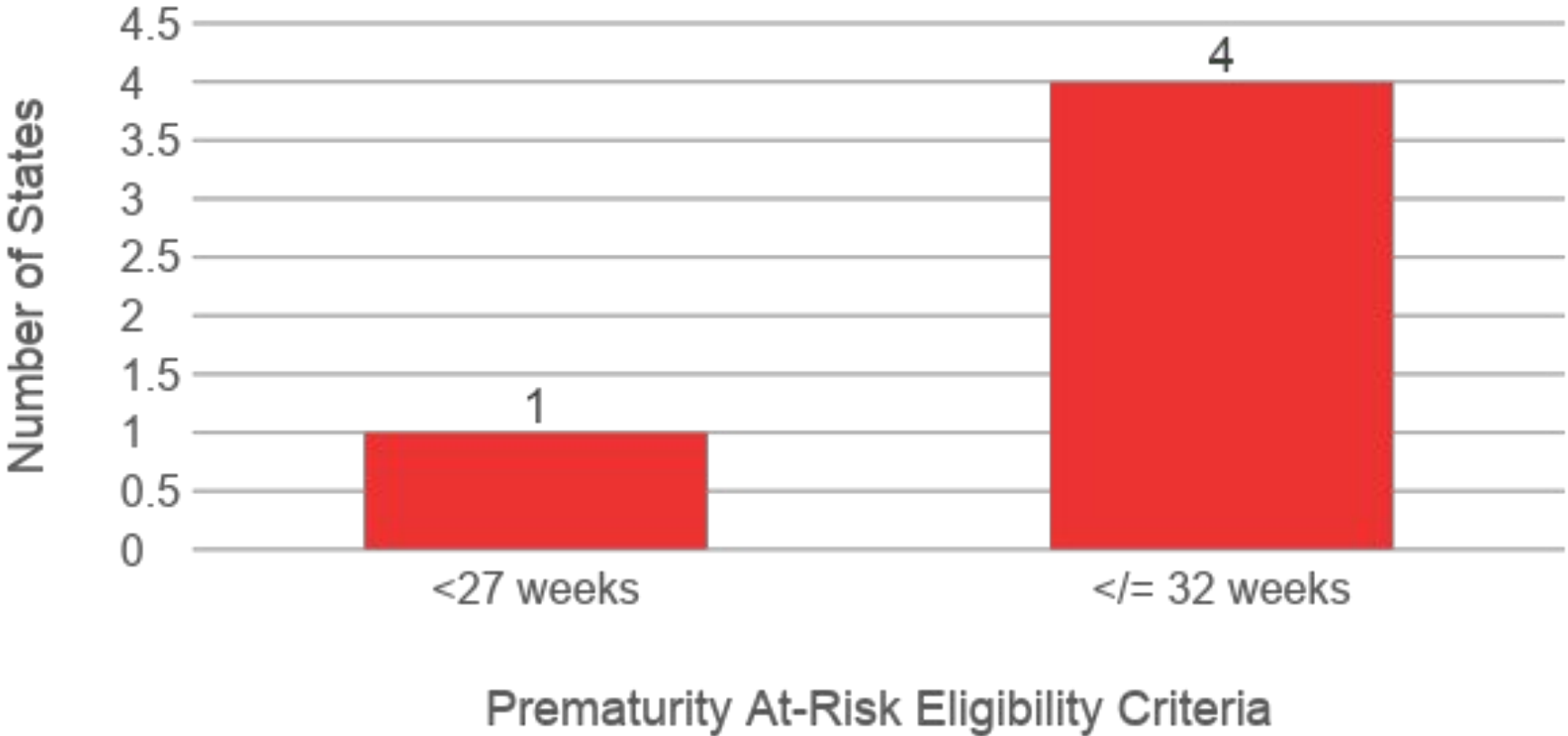
8 states provide services to children at risk for developmental delay:

- 7 of the 8 states do not include LBW as a diagnosed condition.
- None of the 8 states include prematurity as a diagnosed condition.
- 7 of the 8 states include LBW as a risk factor.
- 5 of the 8 states include prematurity as a risk factor.
- In 3 of the 8 states, children with LBW or prematurity need to have multiple child or family risk factors to be eligible for services under the at-risk category.

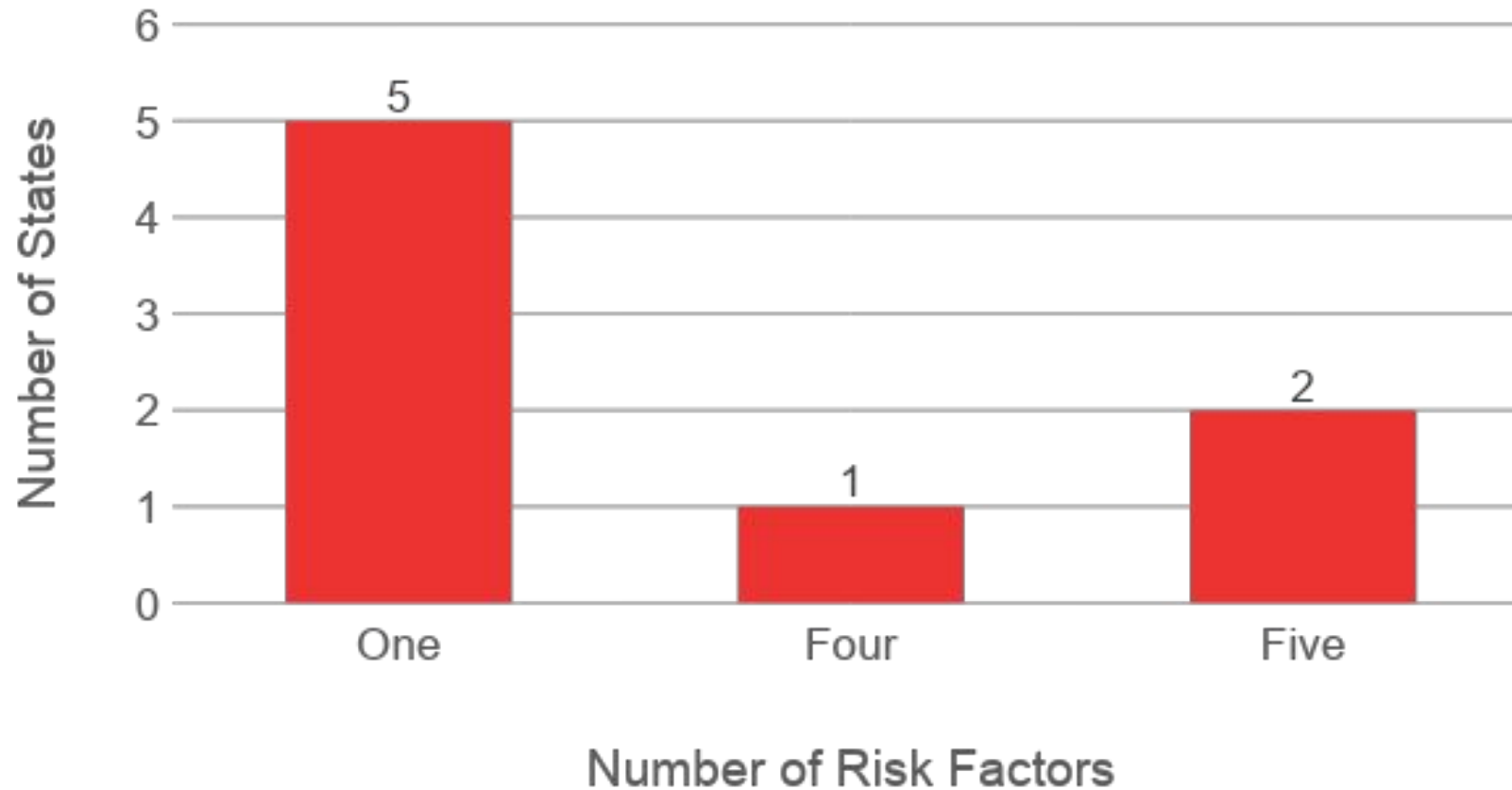
Of the 7 states that include at-risk criteria on birth weight, the number of states with each birth weight.



Of the 5 states that include at-risk criteria on prematurity, the number of states with each weeks of prematurity.



The number of risk factors required for eligibility under at-risk.



Take Aways

- Almost half of states (26) include LBW as a diagnosed condition.
 - Only 12 meet the recommendation from the DEC Position Statement.
- Only 13 states include prematurity as a diagnosed condition.
- For a few states, LBW and prematurity can be used for eligibility under at-risk.
- Informed clinical opinion can be used to establish eligibility but we don't know how it is used with LBW/premature infants and toddlers.
- **In many states, LBW/premature infants and toddlers must demonstrate developmental delay before they are eligible for EI.**



Discussion Questions

- What do these state data say to you?
 - Should we be enrolling more LBW/premature babies and enrolling them earlier?
 - What is your experience enrolling LBW/premature babies in EI?
 - How can collaborative relationships or initiatives (e.g., NICUs, follow-along clinics, family-based organizations) support earlier referral and enrollment?
 - What kind of advocacy needs to happen for the DEC Position Statement to become widespread practice?

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