

Birth Anomalies, Not Birth Defects: Reducing Stigma Through Language

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Birth Anomalies Surveillance System
(BASS)



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Role of community partner critical

Oregon Family to Family Health Information Center (ORF2F HIC)

- Family/caregiver support to navigate complex health systems for children with special health needs
- Parent led, variety of health conditions represented

Oregon Birth Anomalies Surveillance System (BASS)

- Established 2011 (12 birth anomalies)
- CDC funded 2016 (50 birth anomalies)
- Passive surveillance system
- Rely heavily on ORF2F HIC to provide family support



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BASS advisory meeting 2018

- Ask: publicize NBDPM 2019 toolkit and promote birth defects prevention tips.
 - Feedback:
 - Language problematic (birth defects = defective child)
 - How we talked about birth defects reinforced stigma (E.g. birth defects prevention)
 - Campaign not relevant to parents/caregivers of children with special health needs



"I will not publicize the NBDPM toolkit. It's offensive to the families I work with."



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Straddling both a medical model and cultural model

- Didn't fit perfectly into either
- Population health - focus is general population
- Disability rights advocacy – encouraged “new” paradigm for how to view and talk about birth anomalies

Perceptions of NBDPM

- Critical, urgent, fatal framing
- Alarmist, depressing tone
- Preventing conditions

Disability Rights Advocacy

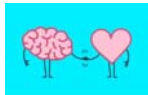
- Non-fatal experiences lacking
- Sensitive, strength based
- Source of pride, identity, community



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Can we do we do both?

- Reframe commonalities (healthy pregnancy)
- Empathic prevention messages
- Pivot brand image (we care, trustworthy)
- Will our messages be more effective this way?



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Outcome 1: Acknowledged stigma

- Brought ORF2F HIC's feedback to NBDPN Education and Outreach Committee
 - End result: Support of colleagues and leadership led to honoring community voices



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Calling out stigma - NBDPM 2020 toolkit

In this toolkit, the term "birth defect" is used to describe an anatomical/ biological difference or anomaly. The National Birth Defects Prevention Network (NBDPN) understands that not all family members view their child as having a "defect" and may reject the use of this term. "Birth anomaly" and "physical difference" for example, are two options of wording that may carry less of a negative connotation, while still acknowledging an anatomical difference. Parents of children who experience these physical differences often focus on "sameness" rather than "different-ness". Parents and advocates work hard to reduce the stigma that may come with their children's physical differences. NBDPN is engaged in ongoing conversations about the use of this term and values the perspectives of community members most closely affected by this issue.



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Outcome 2: Developed inclusive language

- Relationship with ORF2F HIC led to other opportunities
 - Oregon Council on Developmental Disabilities (OCDD)
- Governor's Proclamation
 - Address stigma
 - Balance view of birth anomalies
 - Use nurturing and supportive tone
 - Shatter stereotypes
 - Reinforce new way of thinking about people with birth anomalies



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Other partnership insights

Partners concerned with:

- Blaming families, especially women for having a baby with a birth anomaly
- Sole responsibility for behavior change on the mother (E.g. family vs. mother)
- High expectations for children with birth anomalies (contrast medical system)
 - When families adopt high expectation, children rise to those expectations



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Governor's Proclamation

The Centers for Disease Control observes National Birth Defects Prevention Month each January, and although birth anomalies are sometimes referred to as birth "defects", persons affected are not "defective."

Early identification and intervention services, [family peer support](#), and [community connections](#) [improves children's and families' lives and enrich our communities.](#)

We can all encourage children with birth anomalies to meet their full potential and lead important roles in our communities without limits.



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More on content of Governor's Proclamation

Removed:

- "Common, costly and critical" language
- Removed infant deaths statistic



Included

- Prevention messages (2/5)
- Statement about barriers (systemic discrimination) to achieving prevention tips (behavioral)
- Replaced "National Birth Defects Prevention Month" with "Oregon Birth Anomalies Awareness Month"



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Outcome 3: Stronger relationships, stronger product

- More robust and refined product
 - Multidimensional
 - Ethical, aligned with values
 - Proud of work
- Strengthened relationships with our community partner
 - "I love it!...I am very happy with it in this form. I will be proud to point this out to everyone I know."
 - Discovered an ally for our work (OCDD)



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9 Approaches to working with partners to reduce stigma

1. Solicit feedback
 - Provide seat at the table (advisory committee)
 - Include partners from beginning stages of work
2. Be receptive to feedback
 - Mindset
 - Partners are experts of their own lived experience, not state staff
 - Be humble
3. Be proactive with feedback
 - Monthly meetings, revisit how to make this educational campaign language better together
 - Progress takes time (product or relationship)



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9 Approaches to working with partners to reduce stigma cont'd.

4. Use position/power to advocate for community partner's message
 - Pull feedback into workgroups where partners are absent
 - Continue to involve partners in work, as group permits
5. Okay to make mistakes
 - Poor choice of words, used incorrect language
6. Apply lessons learned to all areas of work
 - Website language
7. Close the loop with gratitude
8. Reciprocate favors to grow relationship



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And lastly, give credit where credit is due

A special thanks to our community partners and advocates who helped us to do our work better.

- Tamara Bakewell (ORF2F HIC)
- Lydia Dennehy (ORF2F HIC)
- Leslie Sutton (OCDD)
- Alice Miller (OCDD)
- Joanne Rogovoy (MOD)



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- Mattie Jensen - Minnesota Department of Health
- Shelby Despain - Utah Department of Health

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To connect with the advocates like ORF2F HIC in your state,
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Thank you!



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