

Birth Defects Surveillance Program | Activities Checklist

Updated September 2024

The Activities Checklist and corresponding Activity Cards should be completed after the Agencies Checklist. This list is separated into two types of activities:

Core activities are recommended activities that should be done on a regular basis. Your program likely already contributes to these, or has the capacity to contribute to these activities, in some way or another.

Enhanced activities are aimed to streamline the referrals system across partners. Your program likely has valuable contributions that other partners haven't realized.

How to fill this out guide:

1. This checklist is intended to act as a summary snapshot of your BDSP's activities.
2. The activities listed are separated into two categories Core and Enhanced.
3. Clicking on the activity in each row will bring you to its corresponding activity card.
4. Filling out the fields in each row will populate the corresponding fields in the agency cards below.
5. Please reference this Impact Matrix guide to determine your designations (<https://mchwdc.unc.edu/resources/impact-matrix/>)
6. You are welcome to jump around this list and fill out cards and prompts in any order you like.

Core Activities

Recommended activities that should be done on a regular basis; your program likely already contributes to these activities in some way.

Activity	Are you currently engaged in this activity?	Impact Matrix Designation
Assess your BDSP referrals activities		
Sharing aggregate data for program planning		
Producing informational materials or brochures		
Community engagement activities		
Engaging with families/PWLE		

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Enhanced Activities

Activities that aim to streamline the referrals system across partners; your program likely has valuable contributions that partners haven't realized

Activity	Are you currently engaged in this activity?	Impact Matrix Designation
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Establish or engage in parent advisory committees

Share line level data with partner agencies

Align referrals process across agencies

Build a list of Birth Defect conditions that "trigger" automatic referral/eligibility/etc. based on age at time of consideration

Assess and update regulations and policies to reduce barriers for inter-agency/org referrals processes

Assess your BDSP referrals activities

SDOH Relevance:

Health Care Access and Quality and Education Access and Quality

Properly referred children should have timely access to:

1. Care providers that can treat and manage their health condition(s) and
2. Appropriate service providers that help build the developmental skills to engage with the world around them.

Example General Next Steps:

Annually, quarterly, monthly:

1. Identify whether ""referred"" vs ""not referred"" cases are being differentiated
2. Assess where cases could have been referred but seemingly were not
3. Compile list for cross-reference with appropriate agencies when needed

Are you currently engaged in this activity?

Impact Matrix Designation

Which partners could you work with to reinforce your engagement within this activity?

How does the SDOH relevance re-frame existing opportunities or anticipated challenges in how your program contributes to this activity?

How can families be included, provide insight, and/or help guide the activities?

Sharing aggregate data for program planning

SDOH Relevance:

Economic Stability and Neighborhood and Built Environment

Accurate and timely data can provide decision makers and funders a better understanding of areas that need the most attention and direct spending to support the necessary infrastructure.

Example General Next Steps:

Annually, quarterly, monthly:

1. Identify and meet with Title V Directors/coordinators (or other agency)
2. Consider what kinds of data the BDSP collects vs other programs
3. Determine if there are overlapping data points and where any gaps can be bridged"

Are you currently engaged in this activity?

Impact Matrix Designation

Which partners could you work with to reinforce your engagement within this activity?

How does the SDOH relevance re-frame existing opportunities or anticipated challenges in how your program contributes to this activity?

How can families be included, provide insight, and/or help guide the activities?

Producing informational materials or brochures

SDOH Relevance:

Social and Community Context

Increasing the awareness of the BDSP and what the program can do/provide for the broader community can enrich the support that families with birth defects can access.

Example General Next Steps:

Annually, quarterly, monthly:

1. Determine type of information to include in brochure: health tips for birth defects awareness; connecting to peer groups; highlighting how screening and surveillance activities helps support families of children with birth defects
2. Include appropriate partners in building out the brochure
3. Develop dissemination/distribution strategy with partners

Are you currently engaged in this activity?

Impact Matrix Designation

Which partners could you work with to reinforce your engagement within this activity?

How does the SDOH relevance re-frame existing opportunities or anticipated challenges in how your program contributes to this activity?

How can families be included, provide insight, and/or help guide the activities?

Community engagement activities

SDOH Relevance:

Neighborhood and Built Environment

In addition to members of the general public, consider "community" to also include the agencies and organizations that work in parallel spaces. Building these relationships can help create alignment in goals and objectives to benefit the overall community.

Example General Next Steps:

Annually, quarterly, monthly:

1. Select date/event where program staff can attend and engage with non-program staff (scope can be inter-dept or outwards towards the public).
2. Determine the purpose of attendance: sharing information, supporting parallel program, create connection, etc.
3. Post-event, conduct necessary follow-ups and assess for improvements

Are you currently engaged in this activity?

Impact Matrix Designation

Which partners could you work with to reinforce your engagement within this activity?

How does the SDOH relevance re-frame existing opportunities or anticipated challenges in how your program contributes to this activity?

How can families be included, provide insight, and/or help guide the activities?

Engaging with families/PWLE

SDOH Relevance:

Social and Community Context

Having families be more connected to public health systems and resources intersects across multiple aspects of social determinants. It can build community both within the public health work the family is engaged in and their normal daily lives; allows state workers to receive appropriate feedback to improve the neighborhoods and built environments; and can provide additional supplemental economic security if compensation is available to participation.

Example General Next Steps:

Annually, quarterly, monthly:

1. Identify and contact Family to Family Health Information Center representative
2. Explore how to connect with other local support organizations and find other opportunities for engagement
3. Assess where they are actively involved in other aspects of public health initiatives (bonus if they are included in referrals systems already)
4. Consider where those intersections can inform the BDSP's activities and referrals work

Are you currently engaged in this activity?

Impact Matrix Designation

Which partners could you work with to reinforce your engagement within this activity?

How does the SDOH relevance re-frame existing opportunities or anticipated challenges in how your program contributes to this activity?

How can families be included, provide insight, and/or help guide the activities?

Establish or engage in parent advisory committees

SDOH Relevance:

Activating family engagement in the decision-making process allows for appropriate incorporation of how programs/resources are perceived and utilized within the community and reveals where improvements can be made to better support the neighborhoods and communities that the programs serve.

Example General Next Steps:

Annually, quarterly, monthly:

1. Connect with a family representative (Family Delegate, FTF, etc.) and identify meetings to reciprocally attend
2. Work with the representative in your jurisdiction to identify related and local organizations that bring families into decision-making
3. Determine the structures of the advisory committee to include items like frequency of meetings, power-sharing procedures, terms of service, etc.

Are you currently engaged in this activity?

Impact Matrix Designation

Which partners could you work with to reinforce your engagement within this activity?

How does the SDOH relevance re-frame existing opportunities or anticipated challenges in how your program contributes to this activity?

How can families be included, provide insight, and/or help guide the activities?

Share line level data with partner agencies

SDOH Relevance:

Activates cross agency efforts in emergent situations.

Example General Next Steps:

Annually, quarterly, monthly:

1. Identify the condition/situation to be shared with relevant agencies.
2. Conduct outreach to additional partners to confirm if their data may show similar trends.

Are you currently engaged in this activity?

Impact Matrix Designation

Which partners could you work with to reinforce your engagement within this activity?

How does the SDOH relevance re-frame existing opportunities or anticipated challenges in how your program contributes to this activity?

How can families be included, provide insight, and/or help guide the activities?

Align referrals process across agencies

SDOH Relevance:

Even with appropriate referrals procedures in place, the burden to seek out and receive care is still on the families. By aligning referrals processes, a BDSP and its partners can better identify actions to ease the navigational burden for families.

Example General Next Steps:

Annually, quarterly, monthly:

1. Identify touchpoints with any agency/org/etc. from the child/family perspective
2. Establish timeline of referral activities: initiating referral, contact and enrollment or deferment, follow up, any resulting actions/outcomes
3. Identify potential redundancies to streamline touchpoints
4. Establish appropriate timeframes for respective entities to follow-up

Are you currently engaged in this activity?

Impact Matrix Designation

Which partners could you work with to reinforce your engagement within this activity?

How does the SDOH relevance re-frame existing opportunities or anticipated challenges in how your program contributes to this activity?

How can families be included, provide insight, and/or help guide the activities?

Build a list of Birth Defect conditions that "trigger" automatic referral/eligibility/etc. based on age at time of consideration

SDOH Relevance:

Building and/or contributing to a comprehensive list of developmental conditions can help streamline the process for all agencies involved, reducing overlapping administrative burdens, and creating a stronger built environment in which service providers are working within. This shift can reduce the time families spend navigating these resources and allow them to focus on caring for their child.

Example General Next Steps:

Annually, quarterly, monthly:

1. Identify existing lists of conditions that trigger automatic eligibility for different programs within your state
2. Compare to see where BD conditions are included
3. Determine where conditions could be moved/added/deleted so that families can more easily navigate the referrals systems
4. Consider stages of development across the lifespan for different conditions and provide adjusted recommendations for follow up

Are you currently engaged in this activity?

Impact Matrix Designation

Which partners could you work with to reinforce your engagement within this activity?

How does the SDOH relevance re-frame existing opportunities or anticipated challenges in how your program contributes to this activity?

How can families be included, provide insight, and/or help guide the activities?

Assess and update regulations and policies to reduce barriers for inter-agency/org referrals processes

SDOH Relevance:

Regulations and policies create the working environments that can facilitate or obstruct essential surveillance and referrals activities. Reviewing big and little p policies with cross-agency perspectives can help align where facilitators can be reinforced, where obstructors can be broken down, and what suggested changes can be made to improve the overall regulations and policies that guide this work.

Example General Next Steps:

Annually, quarterly, monthly:

1. Identify and review existing legislation/policy/etc. regarding birth defects and referrals
2. Determine how these policies may or may not be conducive to the larger referrals network overall.
3. Consider other partners that the policies impact and if revisions would be harmful or beneficial

Are you currently engaged in this activity?

Impact Matrix Designation

Which partners could you work with to reinforce your engagement within this activity?

How does the SDOH relevance re-frame existing opportunities or anticipated challenges in how your program contributes to this activity?

How can families be included, provide insight, and/or help guide the activities?