



The National Down Syndrome Congress (NDSC) is a member-sustained, nonprofit organization, which works to promote the interests of people with Down syndrome and their families through advocacy, public awareness, and information. We appreciate the opportunity to comment on the draft of the Early Childhood Family Engagement Policy Statement from the U.S. Departments of Education and Health and Human Services (HHS). NDSC strongly supports this draft policy statement and has recommendations for additional language, which would make the final policy statement more effective.

The draft policy statement includes many important assertions about the critical role that family engagement plays in any child's success from their early years to their early grades in school. This is especially true for parents of children with Down syndrome who get involved with the local school and HHS systems as newborns for early intervention. Family engagement continues to be important all through the school years. Hopefully this policy statement will lead to a strong foundation of engagement with families as they move through the grades. However, we also urge the development of another policy statement policy addressing meaningful engagement with older students and their families. The focus on the students as self-advocates should increase in later grades.

Purpose

The Purpose section of the policy statement focuses on family engagement with respect to their individual child's development. **We recommend that there also be a reference to the importance of family engagement at program and policy levels, as well.**

Overview

It is also important for successful family engagement to value the contributions of family leaders and organizations at the local and state level, such as NDSC's affiliates across the country.

- **We recommend the addition of a bullet on pages 5, which expresses that one of the reasons family engagement is not equally valued or implemented across early childhood and elementary school systems is that systems are not partnering with diverse family leaders and family organizations to plan, implement and evaluate the effectiveness of family engagement approaches and activities.**

- **We also recommend the addition of language on page 5, which states that family engagement is a shared responsibility that requires partnerships with family leaders and family organizations, including state/local community-based disability organizations that serve families, Parent Training and Information Centers, Community Parent Resource Centers, Family to Family Health Information Centers, PTAs, and any state/local parent advisory councils or committees.**

Principles

NDSC strongly supports the ideas behind all the principles laid out in the draft policy statement. Below are our recommendations for strengthening some of the principles.

As the policy statement points out, “engagement” must be personalized for each family and there must be two-way communication which demonstrates that the family’s input is not merely requested, but also valued. Too often parent “engagement” is done by rote (e.g. attaching a parent statement to an IEP without discussion). These attempts at “family engagement” erode trust because the family’s input was not really considered or integrated into team decision-making. **We recommend that Principle 2, regarding equal partnerships between families and professionals, go beyond valuing family input and assert that the input should be fully considered and integrated into decision-making.**

Even in the early years, children can begin to learn self-determination and self-advocacy skills. This should be a component of family engagement. **We recommend that Principle 6, regarding building staff competencies, include a reference to professional development focused on building the children’s self-determination and self-advocacy skills, including children who require communication supports.**

Principle 7, regarding family capabilities and connections is important, but there is no mention of the many organizations that already exist as resources. The “connections” piece of Principle 7 should include connecting families with these organizations. **We recommend the addition of a statement in Principle 7 that underscores the importance of connecting families to organizations such as state/local community-based disability organizations that serve families, Parent Training & Information Centers, Community Parent Resource Centers, PTAs, and any state/local parent advisory councils or committees. Also, the family organizations’ capacity-building roles should be supported financially, as well as with policies and practices.**

Principle 9, regarding the need to continuously learn and improve should specifically mention the importance of family feedback. **We recommend the addition of the words “including family feedback” after the reference to collecting and analyzing data.**

Recommendations for State Action

NDSC strongly supports the policy statement's recommendations for state action. Below are our suggestions to strengthen their impact.

The "Plan and Prioritize" recommendation talks about ensuring that families have input in the plan development. Families provide input all the time, just to see it ignored. This is a big reason some families disengage and/or lose trust in the system. **We suggest adding language that ensures family input will be considered and integrated into the plan development process.**

The second bullet under the "Invest and Allocate" recommendation refers to the establishment or enhancement of statewide technical assistance. **We suggest adding an example, which would state: Provide additional funding to federally-designated Parent Centers to engage in dual capacity-building activities at local levels to enhance parent engagement for parents of children with disabilities.**

The recommendation "Establish Policies that Support Parent Engagement" should be done in consultation with family organizations. **We suggest adding the following statement: Establish state policies that require district and school administrators and staff to partner with local special education parent advisory groups and community-based disability groups that serve families to evaluate current family engagement policies and practices, make recommendations for improvement, assist in implementation of improvement approaches, and evaluate their impact.**

The recommendation "Establish Workforce Capacity Building that Supports Family Engagement" does not include some key elements. **We suggest broadening the title of the recommendation to also refer to Family Capacity Building. In the discussion section for this recommendation we suggest a sentence specifying that relevant professional development opportunities should be provided to family organizations and family leaders, including self-advocates. We also suggest that professional development should also focus on building children's self-determination and self-advocacy skills, in order to include the child in "family engagement" as soon as possible.**

The recommendation "Develop and integrate family engagement indicators into existing data systems" could benefit from an additional bullet with respect to students with disabilities. **We suggest adding a bullet about using data from family organizations such as Parent Centers, as well as working with family organizations to develop, disseminate, and analyze results of surveys, focus groups, and other mechanisms to obtain family feedback.**

Recommendations for Systemic Family Engagement at the Local Level

NDSC strongly supports the recommendations made in the draft policy statement for systemic family engagement at the local level. A very important point is made about providing access to families. Too often parents encounter difficulty when they request opportunities to visit their child's classroom. Below are our suggestions to strengthen the impact of the local recommendations.

The "Plan and Prioritize" recommendation talks about ensuring that families have input in family engagement plan development. **We suggest adding language that ensures family input will be considered and integrated into the plan development process, including input from local disability organizations that serve families.**

In the "Family Connections" example for the "Establish Policies that Support Family Engagement" recommendation, there is no mention of connecting families to local disability organizations, such as NDSC's affiliates, as a means for bringing families together. **We suggest referencing a connection to local disability organizations that serve families.**

In the "Families as Decision Makers" example for the "Establish Policies that Support Family Engagement" recommendation, the discussion focuses on preparing families to be decision makers. However, in the boxed list titled "Creating Opportunities for Family Engagement" the first bullet talks about providing information about goals, learning approaches and strategies to families with no mention of families being included in making decisions on these topics. It is common practice for family engagement related to students with disabilities to be limited to informing parents about decisions. **We suggest that this section include a statement that teachers and providers receive training on meaningfully including families of children with disabilities in the decision-making process. We also suggest that this section would be a good place to mention preparation of children to be self-advocates. They should be included, in developmentally appropriate ways, in decisions about their services and supports from a young age.**

Resources

In the section on Resources for Families many important links are missing. **We recommend adding the following links to that section, as well as links for various national disability organizations serving families, such as the National Down Syndrome Congress www.ndsccenter.org, www.parentcenterhub.org (National Center for Parent Information and Resources), www.fv-ncfpp.org/ (National Center for Family/Professional Partnerships), www.nhsa.org/our-work/families (National Head Start Association Resources for Families), www.pta.org/ (National PTA), www.p2pusa.org/ (Parent to Parent USA), www.ffcmh.org (National Federation of Families for Children's Mental Health), and www.servingongroups.org**