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Involvement of Youth with Disabilities in State-Level Decision Making

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During the National Association of State Directors of Special Education's (NASDSE) 2005 annual meeting, a panel of youth representatives challenged states to do a better job of including youth with disabilities in state-level decision making (e.g., as members of state advisory panels [SAPs] and/or transition councils). State directors of special education enthusiastically accepted this challenge. The purpose of this document is to describe several states' current efforts to meet this challenge. The document includes the perspectives of both state education agency (SEA) representatives and youth representatives from six states. Project Forum at NASDSE completed this document as part of its cooperative agreement with the U.S. Department of Education's Office of Special Education Programs (OSEP).

DATA COLLECTION

In February of 2007, Project Forum conducted a survey of states to determine which were making efforts to include youth with disabilities in state-level decision making activities. Thirty-two states responded. Project Forum then worked with staff from the IDEA Partnership to review survey findings and identify states for follow-up interview.¹ In collaboration with a representative of the National Youth Leadership Network,² Project Forum developed two interview protocols—one for SEA representatives and one for youth. Interviews were conducted during March 2007 with interviewees from *Illinois, North Dakota, Pennsylvania, Nebraska, Virginia* and *Wisconsin*. Most were conducted via telephone, with the remainder being conducted via e-mail (in the case of interviewees who were deaf-blind or used augmentative and alternative communication). Interviews were transcribed and analyzed using Atlas.ti, a software program designed to aid in the analysis of qualitative data. Interview findings are reported in the following section of this document.

¹The IDEA Partnership, an OSEP-funded project, sponsors a community of practice addressing secondary transition issues and has identified several states that are working to include youth in state-level decision-making relating to transition. More information on this work can be found at www.sharedwork.org.

² The National Youth Leadership Network (NYLN) is a non-profit organization dedicated to advancing the next generation of disability leaders. For more information on NYLN, see nyln.org.

FINDINGS

Survey Results

Of the 32 states responding, 17 described including youth with disabilities in one or more aspects of state-level decision making. Fifteen include youth as members of their State Advisory Panels (SAPs), four include youth as members of their state-level transition councils, and five include youth in one or more of the following ways: as members of committees (e.g., strategic planning, mental health and/or traumatic brain injury committees) or speakers at SAP meetings and annual state-wide transition conferences. Five states plan to add a youth member to their SAPs in the near future and a sixth state is in the process of building a youth leadership network that will serve in an advisory capacity to both the SAP and the state's Vocational Rehabilitation Council.

Interview Results

Interview results are reported in two separate sections. Youth involvement from the perspectives of the six SEA representatives is presented followed by a discussion of youth involvement from the perspectives of the six youth representatives.

SEA Representative Perspectives

Background

Most efforts to include youth with disabilities in state-level decision making are relatively new. *Pennsylvania* appointed a youth to the SAP as far back as 1994 and has done so ever since. The state has also included a youth representative on its transition council for at least 10 years. Other states interviewed began including youth more recently. For example, an *Illinois* statute has required since 2000 that at least one student with a disability serve as a member of the SAP. *Virginia* appointed a youth to serve on its SAP in 2005 after including youth in a number of transition-related activities. Youth representatives were first appointed to *North Dakota's* SAP and transition council in 2006. Also in 2006, *Wisconsin's* SEA received a grant from the Department of Health and Family Services enabling the state to convene a youth transition advisory board that serves in an advisory capacity to the Wisconsin Statewide Transition Initiative. *Nebraska's* efforts to develop a youth leadership network are in the formative stages and SEA staff hope to appoint youth by Fall 2007. The network will serve in an advisory capacity to both the SAP and the state's Vocational Rehabilitation Council.

According to most interviewees, the purpose of including youth with disabilities was to provide a first-hand perspective on what does and does not work in terms of special education services and supports. In the words of one, "When we don't understand [the youth] perspective, it's because they're not at the table helping us plan." The interviewee from *Nebraska* stressed that the inclusion of youth is also intended to help youth develop leadership skills and network with one another.

Youth Involvement in State-Level Decision Making

Interviewees stressed that the role of the youth representative on their SAPs and transition councils was essentially the same as that of any other council member. Responsibilities include attending meetings, reviewing policies and plans, and participating on committees. In addition, members of *Wisconsin's* youth transition advisory board receive training in developing their personal “stories” and are expected to speak publicly at events throughout the state. They are also responsible for governing the advisory board, and are in the process of identifying their goals and objectives.

A number of states described other ways, in addition to serving on state-level advisory boards (i.e., SAPs and transition councils), in which they are working to include youth with disabilities in state-level decision making. For example:

- *Pennsylvania, North Dakota* and *Virginia* invite youth to share their perspectives as part of panel discussions during the states’ annual transition conferences.
- *Virginia's* SEA pays for one youth representative and one family from each of the state’s regions to attend the annual transition conference. The SEA—in collaboration with the Department of Vocational Rehabilitation and various institutions of higher education (IHEs)—also sponsors a number of outreach events on college campuses each year that reach hundreds of students with disabilities who are interested in learning more about post-secondary education opportunities.
- *Wisconsin* and *Nebraska* are conducting an inventory of resources (both activities and curriculum materials) that are already available in their states to support leadership by youth with disabilities.

According to interviewees, outreach is usually conducted informally, by contacting LEA and building-level administrators, teachers, parent training and information centers (PTICs), regional training and technical assistance centers, IHEs and disability-related organizations. *Nebraska* plans to hire a facilitator for its youth leadership network, and one of the facilitator’s duties will be to recruit youth members from around the state.

Only a few states reported having formal eligibility criteria for youth representatives. While some states include youth representatives up to the ages of 28 or 30, other states require that youth representatives be currently enrolled in high school. Interviewees from *Wisconsin* and *Nebraska* (states that include or plan to include approximately 8-10 youth representatives at a time) also described efforts to recruit youth representing a range of disability categories, ethnicities, ages, regions within the state and transition experiences. In *Pennsylvania* and *Illinois*, the names of youth nominees are submitted to the governor for approval. State term limits range from one to several years.

Training and Supports

Interviewees described a range of training opportunities and other supports available to youth representatives. All states offer some type of orientation for SAP members, but nothing specifically tailored to its youth representatives. Orientation materials may include laws, rules, meeting protocol, information on how motions are made, roles of committees and officers and minutes from previous meetings. Interviewees also reported providing reimbursement for meeting-related expenses, including transportation, lodging, meals and costs associated with personal care attendants and/or interpreters. *Wisconsin* and *Nebraska* offer, or plan to offer, stipends to offset the costs of youth representatives attending meetings. To minimize travel time, *Wisconsin* and *Illinois* frequently uses teleconferencing as an alternative to face-to-face meetings and *Nebraska* is considering the possibility of convening three or four regional youth councils throughout the state rather than one centralized council. *Pennsylvania* now holds its SAP meetings in a hotel as opposed to the department of education in order to accommodate the needs of members—including a youth representative—using wheelchairs.

Several interviewees stressed the importance of “growing” their own youth leaders, and described state-level efforts to provide youth leadership development. For example:

- *Wisconsin* recently completed a comprehensive state-wide training of staff to support youth advocacy and leadership. The SEA hired two young adults with disabilities as consultants to develop a training manual³ on cultivating youth leaders and to facilitate a combined training of both Wisconsin State Transition Initiative regional coordinators and newly appointed youth representatives. Each of the 12 regional coordinators then used the training manual to train several hundred teachers throughout the state. Youth representatives receive ongoing leadership training and the state plans to convene a youth development leadership practice group made up of both youth and other stakeholders.
- Virginia’s SEA helps sponsor youth attendance at the Virginia Board for People with Disabilities’ annual weeklong leadership forum for 25 youth. Participants have opportunities to meet with the governor and their state representatives. The SEA is also spearheading a self-determination project that includes the development of a self-determination curriculum for elementary, middle and high school students.
- *Nebraska* plans to provide ongoing leadership training to members of its youth leadership network.

Benefits of Youth Involvement

Interviewees agreed that the greatest benefit of youth involvement was getting a youth perspective on issues such as inclusion and transition. One interviewee said youth participation helps other members of the SAP “really hear what it is youth need, instead of making

³ The *Youth Leadership and Development: Facilitator’s Guide* (Mooney & Horne, 2006) is available at www.sharedwork.org.

assumptions based on what *we* think youth need.” Another stressed that “by having youth tell their stories ... it brings us back to what this is all about.” Several suggested that youth involvement is gradually helping SEAs change the way they “go about doing business”—moving from tokenism to a more systematic inclusion of a youth perspective whenever youth-related issues are being discussed.

Challenges to Meaningful Youth Involvement

Although most interviewees were enthusiastic about youth involvement in state-level decision-making, several admitted that securing meaningful participation by youth has been and/or remains a challenge. In the words of one interviewee, “These kids are not prepared to come to the table and assume a leadership role.” Another noted, “Students get involved; they are sworn in; they come to a few meetings; and they kind of lose interest.” While some attributed these problems to the fact that young people tend to be focused on more immediate concerns (e.g., jobs, school, social engagements), others acknowledged, that the SEA was partially responsible as well. For instance, several suggested that the SEA does not do enough to orient and prepare youth representatives for their state-level roles. Others suggested that it is naturally easier to get youth involved in transition-related councils than in SAPs, because topics addressed by SAPs are often more abstract and less obviously relevant.

Other challenges were also identified. For example, one interviewee noted that there is often a significant delay in approving youth appointments, resulting in high school students who frequently serve for only part of the academic year—not enough time to really make a meaningful contribution. Several interviewees also noted that the fiscal costs of including youth can be prohibitive. For example, *Wisconsin’s* SEA is only able to include as many youth as members of its youth transition advisory board because of the Medicaid Infrastructure Grant (MIG) the SEA receives from the Department of Health and Family Services. Most interviewees mentioned that it was difficult for youth to get release time from work or school in order to attend meetings. Interviewees also noted the fact that students with learning or physical disabilities are more likely to serve as youth representatives than are students with autism or significant cognitive impairments.

Policy Recommendations

Interviewees made a number of policy recommendations pertaining to the inclusion of youth representatives in state-level decision making. For example:

- Require that youth members be a part of the SAP and other state-level advisory groups addressing the education of students with disabilities.
- Invest in “growing” a statewide network of youth representatives instead of just relying on one individual youth.
- Designate an SEA-level staff person to oversee issues relating to youth leadership activities within the state, or hire and train a youth with disabilities to do this.

- Include a self-advocacy strand specifically for youth with disabilities at annual state-wide transition conferences.
- Seek advice from other states that are modeling best practices in the area of youth involvement in state-level decision making.
- Coordinate SAP meetings with youth-centered activities such as transition conferences in order to improve meeting attendance by youth representatives.
- Create time on SAP meeting agendas for youth representatives to bring up student-related issues.
- Prepare youth representatives prior to meetings so they will know in advance that they will be expected to speak out on a particular issue.
- Extend the cut-off age for participation in order to allow young adults—as well as high school students—to represent the youth perspective.

Youth Representative Perspectives

Background

All six youth representatives were between the ages of 20 and 31 years old and enrolled in college courses and/or employed at the time they were interviewed. Their involvement with the SEA ranged from five months to six years in duration. Several reported having been involved in other leadership activities prior to serving as SEA-level youth representatives (e.g., speaking publicly about their experiences at conferences or serving on disability-related boards).

Interviewees identified several reasons for their involvement in SEA-level decision making. Most commonly, they listed the importance of representing other students with disabilities “at the table,” ensuring that a youth perspective was part of all policy-making discussions and improving the quality of special education services and post-school outcomes. Several interviewees described participation in SEA-level decision making as an invaluable opportunity to learn more about special education in terms of the “big picture” and to advance themselves professionally.

Youth Involvement in State-Level Decision Making

Interviewees from *Illinois*, *North Dakota*, *Pennsylvania* and *Virginia* serve as members of their states’ SAPs; the interviewee from *Wisconsin* serves on the state’s transition council; and the interviewee from *Nebraska* serves on the state’s deaf-blind advisory council. Youth SAP members described participating on a variety of sub-committees including committees on bilingualism, the revision of special education regulations, caseload/class size, inclusive classrooms and secondary transition. *Wisconsin’s* transition council member described speaking publicly about her transition experiences at local, state and national conferences. She also described the excitement she and other youth on the council felt at being granted authority to govern the council themselves.

Most SAP members received some type of generic orientation prior to joining the SAP that included information on SEA policies and meeting procedures. Several also received informal mentorship and/or support from other SAP members. The representative from *Wisconsin's* transition council was the only interviewee who described receiving ongoing leadership and self-advocacy training specifically for youth representatives with disabilities. All six interviewees feel that their opinions are valued by both fellow council members and other state-level policy makers. All reported that they are now comfortable participating in policy-level discussions, although most reported that they initially found such discussions difficult to follow.

Benefits of Youth Involvement

Youth representatives felt that their participation on the SAP and other SEA-level councils served as a tangible reminder to others that whenever youth are being discussed, youth should also be included in the conversation. Youth representatives also described specific ways they had contributed to policy-making discussions. For example, two SAP members—both with learning disabilities—felt that they had made significant contributions to discussions about state-wide adoption of Response to Intervention (RtI) models. Several interviewees described efforts to reach out to and share information with other youth with disabilities. The interviewee from *Virginia*, for example, operates a listserv for youth with disabilities where he posts information on topics pertaining to special education policy and solicits their feedback.

Most interviewees described personal benefits from their involvement in SEA-level decision making including becoming more self-confident, knowledgeable and diplomatic. In the words of one interviewee, involvement has “changed my life because it gave me a voice.” In the words of another, “I feel like I’m important, like what I say matters, and that’s a great feeling.” The interviewee from *Wisconsin* noted that her involvement in the transition council had not only enabled her to meet other youth with similar experiences, but also to develop a more positive attitude regarding her disability.

All interviewees agreed that they would continue to seek out leadership opportunities within the disability arena once they had completed their terms as SEA-level youth representatives. For instance, the interviewee from *Virginia* was recently appointed to the board of the Learning Disability Association. Also, interviewees from *North Dakota* and *Wisconsin* are currently working or planning to work as special education teachers. In the words of one, “I plan to ... get out there and confidently bring hope to kids that might not have hope.”

Challenges to Meaningful Youth Involvement

Most interviewees described one or more challenges to meaningful youth involvement. In the words of one interviewee, “The first time [I attended a meeting] I was overwhelmed—I felt like a duck out of water.” In the words of another, “I thought it would be easy for me to jump in and provide my viewpoint ... but it was amazing how much bureaucracy there was.” Another interviewee noted, “If the young person is selected, and they have no prior experience at all on councils and boards, it’s going to be very confusing.”

Other interviewees described transportation difficulties (e.g., one interviewee uses a wheelchair and usually travels via bus with her mother) and challenges relating to missed classes and/or work. In the words of one, “Taking off work has been tricky.” In the words of another, “As far as losing a day’s worth of pay, that’s the hardest thing, because I have rent and bills I have to pay.”

Four of the six interviewees reported that they did not know any other youth with disabilities involved in state-level decision making. Several speculated that this was in part because of a lack of leadership development opportunities within the state, as well as because many young people do not necessarily recognize the importance of policy-level involvement.

Policy Recommendations

Youth representatives reiterated some of the recommendations made by SEA representatives and generated a number of new recommendations:

- Provide ongoing leadership development and/or self-advocacy programs throughout the state for youth with disabilities in order to train new leaders and provide opportunities for youth to network with other youth.
- Improve outreach to LEAs and schools so that youth and their families are aware of opportunities to get involved at the state level.
- Always include more than one youth representative at a time.
- Create avenues for youth involvement and input that are youth-driven rather than adult-driven.
- Provide comprehensive training and orientation for youth members of state-level councils.
- Pick meeting locations that are accessible via public transportation.
- Conduct teleconferences as occasional alternatives to face-to-face meetings.
- Increase the amount of stipends for youth participants and reduce the turn-around time for reimbursement of meeting-related expenses.

Summary

Survey responses suggest that states are indeed moving toward greater involvement of youth in SEA-level decision making than ever before. Furthermore, all 12 interviewees—both SEA-representatives and youth representatives—agreed that the involvement of youth has resulted in numerous benefits, most importantly, the inclusion of a youth perspective. Significant challenges remain, however, to the meaningful participation of youth—particularly in those states lacking comprehensive leadership development programs. Interviewees provided a number of recommendations on best-practices for including youth in SEA-level decision making. These recommendations should prove useful to states that are considering the addition of one or more youth representatives to their SAPs and/or transition councils.

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