

Policy and Practice Brief:

Conducting Outreach to Transition-Aged Youth

Strategies for Reaching Out to Youth with Disabilities, Their Families, and Agencies that Serve Them

Prepared by

James R. Sheldon, Jr., an attorney with Neighborhood Legal Services (NLS) of Buffalo, New York and Thomas P. Golden, faculty with Cornell University's Employment and Disability Institute and Director of the Work Incentives Support Center, Ithaca, New York.

This is one of a series of articles written for benefits specialists employed by Benefits Planning, Assistance and Outreach projects and attorneys and advocates employed by Protection and Advocacy for Beneficiaries of Social Security programs. Materials contained within this policy brief have been reviewed for accuracy by the Social Security Administration (SSA), Office of Employment Support Programs. However, the thoughts and opinions expressed in these materials are those of the authors and do not necessarily reflect the viewpoints or official policy positions of the SSA. The information, materials and technical assistance are intended solely as information guidance and are neither a determination of legal rights or responsibilities, nor binding on any agency with implementation and/or administrative responsibilities.



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I. Introduction

The Benefits Planning, Assistance and Outreach (BPA&O) and Protection and Advocacy for Beneficiaries of Social Security (PABSS) programs were authorized by the Ticket to Work and Work Incentives Improvement Act of 1999.¹ That law initially created the BPA&O and PABSS programs to serve Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI) cash beneficiaries who are either working or planning to enter the workplace in the future. This legislation was amended by the Social Security Protection Act of 2004 to allow BPA&O and PABSS staff to serve both cash beneficiaries and former cash beneficiaries² who continue to take advantage one of the special work incentives like SSI's 1619(b) Medicaid program or the SSDI provision for extended Medicare benefits.³ For purposes of this policy and practice brief, we will refer to all individuals who are eligible for BPA&O or PABSS services as beneficiaries.

Since their inception in 2001, most BPA&O and PABSS programs have developed outreach strategies for effectively targeting adult beneficiaries, particularly those who are in their mid-20s or older. However, of the over 124,490 beneficiaries served by the BPA&O network as of June 30, 2004, only 7.9% (n=9,821) were under the age of 22 documenting the fact that transition-aged youth with disabilities remain an underserved population. As explained in section II, below, we are defining transition-aged youth broadly to include individuals between the ages of 14 and 25.

The purpose of this policy and practice brief is to provide readers with a resource for planning outreach to transition-aged youth, their parents, and the service providers who work with them (i.e., our “target group”). We will first provide a summary of the laws governing how three key agencies — school districts, state vocational rehabilitation agencies, and the Social Security Administration (SSA) — are expected to deal with this targeted group of young persons with disabilities. We will then summarize some of the special services (or “products”) that BPA&O and PABSS programs have to offer youth and those who work with them. Finally, we will outline strategies that can be used by the BPA&O and/or PABSS programs to reach a higher percentage of youth, their parents, and the service agencies that work with them. Based on the author’s experiences and those of colleagues, some very concrete examples will be used to demonstrate successful outreach approaches.

II. Who Are Transition-Aged Youth?

A. Relevant Criteria Under Special Education Laws, Title I of the Rehabilitation Act, and SSI Regulations

This section focuses, in part, on the definitions used and the mandates of the special education and state vocational rehabilitation (VR) systems to prepare students with disabilities for adult living, learning and earning. With some understanding of the ways that special education and VR systems are expected to work with transition-aged youth, we have a better context for planning our BPA&O and PABSS outreach strategies. A more extensive discussion of these issues appears in an earlier policy and practice brief,

¹ Pub. L. No. 106-170, codified mostly in 42 U.S.C. §§ 1320b-19 et seq.

² 42 U.S.C. §§ 1320b-20(c)(2) (BPA&O programs), 1320b-21(g)(2) (PABSS programs).

³ See 42 U.S.C. §§ 426(b) (extended Medicare benefits), 1382h(b) (section 1619(b) Medicaid).

The Transition from School to Work: The Special Education and State Vocational Rehabilitation Systems' Obligations to Prepare Students with Disabilities for the World of Work, which is available on the Employment and Disability Institute's website at Cornell.⁴ This section also describes how SSA, in its implementation of the SSI and Social Security programs, divides its world into children and adults with age 18 as its demarcation line. As explained in section III, below, an understanding of the mandates governing schools, VR agencies, and SSA may help us to sort out when those agencies will make appropriate partners in our outreach activities.

I. Special Education Definitions and Mandates

The Individuals with Disabilities Education Act (IDEA) is the federal law that governs the delivery of special education services to students with disabilities.⁵ Under the IDEA, the transition years span ages 14 through 21. The 1990 amendments to the IDEA added transition planning requirements to the law. Beginning at age 14, the student's individualized education plan (IEP) must include the transition service needs related to the child's course of study under all applicable sections of the IEP. No later than age 16, a full-blown transition services plan must be included in the student's IEP.⁶ Since a student's right, under the IDEA, to publicly-funded special education services can extend through age 21, if the student does not obtain a high school diploma earlier, the transition planning mandates will continue through age 21 in many cases.

Educators and others who work with students with disabilities rightfully remind us that transition planning is not just about the transition from school to work. Rather, transition planning should focus on a coordinated set of activities that promotes movement from school to all post-school activities.⁷ A practical way of thinking of this is that the special education system and its partners are paving the way for these future adults to live, learn, work, and play — the very things we all aspire to do as adults. For those working in the BPA&O or PABSS context, however, our interventions must be related, in some way, to overcoming barriers to working. As explained in section III, below, this will certainly include any benefits planning or advocacy services related to education (i.e., “learning”) and, in some cases, may also relate to obtaining appropriate housing or housing subsidy benefits (i.e., “living”).

With the exception of the futures planning related to recreational and leisure-time activities, our BPA&O and PABSS program mandates are very closely aligned with the special education systems' transition planning mandates. In fact, through addressing barriers to work, such as transportation, and by enabling beneficiaries to succeed at work with meaningful pay, we may simultaneously pave the way toward fuller access to and enjoyment of leisure-time activity.

2. State Vocational Rehabilitation Agency Definitions and Mandates

Title I of the federal Rehabilitation Act governs state vocational rehabilitation (VR) agencies.⁸ While state VR agencies do incorporate, to some extent, the IDEA-based definitions for transition-aged youth, there is no clear lower age when the VR agency's

⁴ See <http://www.ilr.cornell.edu/edi/PPBriefs.cfm>.

⁵ 20 U.S.C. §§ 1400 et seq. A very comprehensive summary of federal special education mandates is contained in *The Public School's Special Education System as an Assistive Technology Funding Source: The Cutting Edge* (April 2003), available at: www.nls.org/specedat.htm or www.nls.org/pdf/special-ed-booklet-03.pdf.

⁶ 20 U.S.C. § 1414(d)(1)(A)(vii).

⁷ *Id.* § 1401(30).

⁸ 29 U.S.C. §§ 720 et seq.

role begins or upper age for when the role of the VR agency (in transition) ends. Rather, the law envisions some collaborative role as early as age 16, with the VR agency involvement continuing until a vocational goal is achieved. From a practical standpoint, as it relates to our outreach planning, it makes sense to look at the VR agency's role with transition-aged youth as extending in many cases to age 25 or older.

The law contemplates that VR agencies will play an active role in transition planning. The federal regulations, issued by the federal Rehabilitation Services Administration, make it clear that state VR agencies are to be actively involved in the transition planning process with school districts, including: (1) outreach to, and identification of, students with disabilities who may need transition services, as early as possible during the process; (2) consultation and technical assistance to assist school personnel in transition planning; and (3) involvement in transition planning with school personnel that facilitates development of the special education IEP.⁹ In discussing the importance of early involvement of VR agencies in the transition planning process, the comments to the regulations stress that the VR agency should “participate actively throughout the transition planning process, not just when the student is nearing graduation.”¹⁰ Transition services are specifically listed in the VR regulations as an available VR service.¹¹

As part of the VR agency's mandated outreach, the agency must inform students of the purpose of the VR program, the application procedures, the eligibility requirements, and the potential scope of services that may be available as early as possible during the transition planning process. The stated reason for this requirement is “to enable students with disabilities to make an informed choice on whether to apply for VR services while still in school.”¹² In other words, it is the student's and family's choice whether to apply for VR services while still in school. These outreach requirements may make your state's VR agency a very good partner for any outreach plans related to this population.

3. Definitions Under the SSI and Social Security Disability Insurance Programs

Both the SSI and Social Security programs start treating youth with disabilities very differently starting at age 18. This becomes very important to youth, their parents, and service providers who are involved with them. Since this part of transition planning is most often ignored by schools and others, your BPA&O or PABSS program should have a ready product to offer as part of your outreach strategy — that is, your knowledge of the way those benefit programs operate, and how they can be used to meet the needs of youth with disabilities.

a. SSI and Transition-Aged Youth

The SSI program does not use the terminology “transition-aged youth” within its laws, regulations, or policies governing the program. However, the way the program is structured there is a definite division between children and adults at age 18. There are two key differences between the way the SSI program treats children and adults, defined as individuals age 18 or older. One difference relates to the definition of disability; the other relates to the treatment of parental income and resources.

⁹ 34 C.F.R. § 361.22(b).

¹⁰ 66 Fed. Reg. 4424.

¹¹ 34 C.F.R. § 361.48(r).

¹² 66 Fed. Reg. 4424.

Since a major part of transition planning should be to get advance information to students and their families about when benefits become available, some of the changes that occur in the SSI and Social Security programs at age 18 are critical pieces of information that will be part of any message delivered through an outreach and education plan. They will also become very important parts of any long-range benefits planning.

Disability criteria. Adults seeking SSI disability benefits must establish that their disability or combination of disabling impairments prevents them from engaging in substantial gainful activity.¹³ Although individuals with the most severe disabilities may establish disability based on medical criteria alone (i.e., if they have a “listed” impairment¹⁴), the ultimate analysis in many adult SSI cases will focus on the individual’s ability to engage in significant work activity despite a severe disability. By contrast, the disability criteria for children under 18 requires a showing that the disabling impairment or combination of them causes marked and severe functional limitations.¹⁵ Even for older teens, the analysis of disability rarely considers functioning in a work-related setting except as it relates to establishing the marked and severe functional impairment standard. Among advocates who have represented children and adults on appeals involving these differing disability criteria, most would agree that the children’s standard is, most often, the more difficult one to meet.

In the SSI framework, transition to adulthood occurs at age 18. For any individual who has received SSI disability benefits as a child, upon turning age 18 this individual will be subject to an age 18 redetermination. This means that SSA will review the individual’s case at that point to determine if he or she now meets the standard of disability for an adult. If the answer is “yes”, SSI benefits continue; if the answer is “no”, SSI benefits will ordinarily be terminated subject to special provisions that will allow a continuation of benefits if this young adult is engaged in an approved vocational rehabilitation program that is likely to lead to their permanent removal from the disability rolls.¹⁶

Because of the different disability criteria that applies in SSI cases at age 18 some young adults, previously denied benefits under the very strict criteria for children, might now be eligible under the very different criteria for adults. Keep in mind, as noted above, that part of the adult criteria ultimately looks at how the disabling condition affects the person’s ability to function in work settings. This could mean that some young adults, with conditions like severe learning disabilities, might be able to establish disability under the SSI adult criteria because of very concrete proof concerning how the condition affects them in work environments.

Counting of parental income and resources. Under a concept known as “deeming” for children under age 18 the income and resources of a parent or stepparent, who resides in the child’s household, are relevant in determining the child’s financial eligibility for SSI, including the amount of the monthly SSI check if the child is eligible. By contrast, at age 18 the income of parents and stepparents ceases to be relevant. None of the parent or stepparent’s income or resources will be counted in determining eligibility unless that parent/ stepparent is actually making that income or resources available to the child to meet the adult child’s needs for food, clothing, or shelter. For example, if a parent is making monthly child support payments to meet the child’s needs, two thirds of that money will be considered unearned income to the adult child even if that child is 18 or older.¹⁷

¹³42 U.S.C. § 423(d), 20 C.F.R. § 404.1505.

¹⁴See 20 C.F.R. Part 404, Appendix I, Subpart P, Part A (the listing of impairments for adults).

¹⁵42 U.S.C. § 1382c(a)(3)(C), 20 C.F.R. § 416.906.

¹⁶42 U.S.C. § 1383(a)(6)(A).

¹⁷20 C.F.R. § 416.1124(c) (11).

b. SSDI and Transition-Aged Youth

Some children with disabilities may collect Social Security benefits against the earnings record of a parent who is retired, disabled, or deceased. These dependents' benefits, when received before the child turns 18 will not be based on disability; rather, they are based on the status as a dependent child. When the child becomes 18, or 19 if still attending public school as a full-time student, the right to these benefits will end.

For youth with disabilities, the end of entitlement to Social Security dependents' benefits can mean the start of entitlement to a form of SSDI benefits known as Childhood Disability Benefits (CDB), often referred to in the field as Disabled Adult Child's (DAC) benefits. So long as the young adult is at least 18, has a disability that began before age 22, and is seeking benefits on the account of a parent who met or meets the required earnings or insured status requirements for this benefit, the child will be eligible for a monthly DAC check.

B. An Expanded Definition of Transition-Aged Youth for This Article — Ages 14 Through 25

In the context of our BPA&O or PABSS work, the purpose of an outreach effort related to youth with disabilities is to make our benefits planning or advocacy services available while the individual is involved at any stage of the transition planning continuum. Viewed broadly, this continuum spans the ages of 14 through 25.

As noted earlier, the IDEA transition mandates begin at age 14 and continue throughout the remainder of the child's enrollment in the special education program — i.e., through age 21 in many cases. Between the ages of 18 and 21, we will see special education students leaving the public school setting, with or without high school diplomas. Thereafter, these young adults transition into the adult service systems. When the system works as expected, the state VR system would then pick up working with these young adults, if VR agency services will be needed. For some, transition means movement to college; for others, it will mean movement into employment; for still others, it will mean a transition into employment through some form of prerequisite vocational preparation or training. These next steps in the transition continuum might easily take the student through age 22 or 23. For many, the process will expand to age 25 or beyond. For these reasons, we should look broadly at the transition process as extending through age 25.

III.

Determine What Your BPA&O or PABSS Program Has to Offer

As a prerequisite to planning outreach, it is helpful to analyze the special services your program has to offer youth with disabilities. Ultimately, it is these “products” that you will be marketing. As you think through these issues, you should identify which services will be viewed as most important by your target group.

A. The BPA&O and What it Can Offer Youth with Disabilities

The BPA&O project has two primary products to offer youth with disabilities, their parents, and others who work with them: education about benefits and benefits planning. While these services are similar to what the BPA&O project can offer adults, in the author's experience these services may be even more important to youth. This is, in part, because special education personnel have not, historically, looked at benefits information — particularly information about SSI, SSDI, Medicaid, and the work incentives — as an important part of the transition planning process. Moreover, many parents are just beginning to hear about the availability of things such as SSI as their child goes into the transition years. When the child or young adult is receiving SSI, the usual myths about benefits and work often persist, with parents often resistant to having their child work for fear of an immediate end to cash benefits and Medicaid.

There are a number of key pieces of benefits information that will become valuable to our target group, either through an education campaign or through benefits planning services. The following is a representative list that we should consider although this list is in no way exhaustive:

For SSI recipients:

- Describing financial eligibility for SSI prior to age 18 and after age 18
- Alerting the target group that deeming of parental income and resources stops at age 18
- Apprising the target group of inkind support rules that replace deeming when a youth turns 18
- In 39 states and the District of Columbia, explaining that an SSI recipient is automatically eligible for Medicaid
- Explaining how the Plan for Achieving Self Support (PASS) can be used: before age 18, using deemed income from parents to fund future vocational goals; before or after age 18 using child support payments or Social Security income to fund future vocational goals
- Explaining the SSI budgeting rules for earned income and existing work incentives, including the special Student-Earned Income Exclusion for youth up to age 22
- Demystifying the SSI program's age 18 redetermination and ongoing redetermination process
- Explaining that some young adults, previously denied under the children's SSI disability criteria, might now qualify under adult criteria
- Explaining the future application of the 1619(b) Medicaid provisions for individuals who lose SSI benefits because of wages
- Describing for the target group how earnings may make an individual eligible for Social Security on their own earnings record and implications of this transition

For Social Security beneficiaries:

- Explaining how Trial Work Period and Extended Period of Eligibility support the return to work process
- Describing how work incentives can support increased self-sufficiency
- Discussing ongoing availability of healthcare (Medicaid) once an individual begins working and extended Medicare provisions

For both SSI and Social Security:

- If your state has a Medicaid buy-in, explaining how that can protect Medicaid eligibility for working individuals who are unable to access 1619(b) or lose Medicaid as a result of work
- Explaining the services available through your state's VR agency
- Describing advocacy services and supports available through the national Protection and Advocacy network
- Explaining the Ticket to Work and Self-Sufficiency program
- Describing the Continuing Disability Review process and protections that are available
- Discussing the role of the Expedited Reinstatement of Benefits provisions as a work safety net

With these factors in mind, a youth outreach campaign will have two primary goals: to provide quality information to youth, their parents, and service providers to support informed choice; and to build up a higher caseload in which benefits planning services are provided to youth.

B. The PABSS and What it Can Offer Youth with Disabilities

The PABSS program also has two primary products to offer youth, their parents, and service providers: education about a wide variety of benefits and legal rights that can help overcome barriers to work; and legal and advocacy services to challenge denials of those benefits or legal rights.

The issues that a PABSS attorney or advocate can deal with are potentially very diverse and depend only on the issue having some causative connection to a barrier to work. Starting with SSI and SSDI issues, it is important to note that during 2003 the SSA amended PABSS grant conditions to allow representation of individuals on appeals involving SSI or SSDI. There are two limitations on this work: the issues must be work-related; and appeals work cannot involve litigation against SSA (i.e., a PABSS program can represent on appeals up to the Appeals Council level). Probably the most common SSA-related appeals handled involve SSI or SSDI overpayments related to work. Another significant area for appeals would involve adverse SSA decisions related to the SSI or SSDI work incentives (e.g., the rules for determining substantial gainful activity, impairment related work expenses, or subsidized wages).

The following is a representative list of some additional issues that could be involved with PABSS work although this list is in no way exhaustive:

- enforcement of rights under the state VR agency and Ticket to Work programs
- enforcement of rights under the IDEA transition mandates
- the right, under the Americans with Disabilities Act (ADA), to accessible transportation to allow an individual to go to work or attend an educational or training program
- the right, under the ADA, to physical access within a college campus or other educational institution for a person with a physical disability
- the right, under the ADA, to reasonable accommodations in a college curriculum or non-college training curriculum for a person with a learning disability or other cognitive disability
- the enforcement of rights under the federal student loan program (e.g., the right to have a loan deferred or forgiven)
- the enforcement of rights under public and subsidized housing programs (e.g., enforcement of the special earned income disregards for persons with disabilities)
- enforcement of Title I of the ADA barring discrimination in employment
- enforcement of rights under third party insurance plans, such as Medicaid, Medicare, and private insurance plans

In the PABSS context, the youth outreach campaign will also have a two-fold purpose: to educate the target group about these issues; and to build up a larger caseload in which eligible beneficiaries seek to enforce their rights with respect to these issues.

IV. Creating a Foundation for Your Outreach Plan

In this section, the focus is on the ground work you will want to do before you sit down with a design team to begin developing your outreach plan. All too often, we jump too quickly to the plan itself, without taking some preliminary steps as outlined in this section. These pre-development activities need not become an overly time-consuming exercise within your program. However, some purposeful thinking about how to fit this outreach plan into the existing work of your agency, the existing work of your partners, and the existing service delivery system in your state or region of the state will go a long way toward making your plan successful.

A. A Comment on the Cost of Your Outreach Efforts

The budgets of BPA&O and PABSS programs are modest, with no extra pool of funding available to create special materials, pay for advertisements, or run big-scale conferences. On the other hand, an effective outreach and education program will have significant costs, including the extra costs associated with your labor that will not be spent on direct services to beneficiaries.

The first principle you must embrace is that the investment in time and money is worth it. With some exceptions, BPA&O and PABSS programs have not worked with significant numbers of transition-aged youth during their first four years of existence. If you are to reach this target group, you must have a very organized plan to do so. The cost of this plan should be viewed as just one of the costs of doing business.

The second principle you must embrace is that you can reduce the cost of your plan through the contributions of collaborators. Using the analogy of a potluck dinner, you can greatly reduce your agency's out-of-pocket costs and labor time that go into big events and other outreach strategies by soliciting and investing other partners. In the process, these partners will become some of your biggest promoters of both the events you have planned and the services that you offer.

B. Conduct a Self-Inventory of What Your Agency Is Already Doing Well and Build on Those Strengths

Nearly all BPA&O programs are housed within existing agencies, including a number of centers for independent living. The parent agency may have any number of established activities, such as a widely distributed newsletter, a regular radio or cable TV program, or an existing collaboration with a major agency that serves children with disabilities and is quite happy to post any information you give them to a broad-based parent list serve. By using these existing strengths in your outreach plan, you ensure the ability to move quickly with part of your publicity plan, ensuring that you are using a tested method for publicity and minimizing the expense of the effort by using what is already ongoing.

Nearly all PABSS programs are similarly housed within existing agencies, typically statewide Protection and Advocacy (P&A) programs that operate several other advocacy programs, including P&A to the Developmentally Disabled (PADD) and, in many states, the Client Assistance Program (CAP). Your PADD program may already be serving a significant number of youth with disabilities on special education matters and be involved in active collaborations with several parent organizations. Your CAP program may already be in regular communication with your state VR agency, having worked with them in the past on putting together events to reach individuals with disabilities. Here again, using existing relationships as a starting point, you may be able to quickly identify some core partners to assist you with your plans.

C. Define the Outcomes You Are Trying to Achieve

Whether you phrase this part of the analysis in terms of goals and objectives, or outcomes, you will need to finish the sentence: "My agency is doing outreach to transition-aged youth because we seek to". Once you have outlined the ends you are seeking, both you and your partners will have a better sense of what steps you should take to get there.

The following is a list of some of the outcomes your outreach strategy may be trying to reach:

- to educate youth, parents, and others (the target group) concerning the relevant SSI, Social Security and Medicaid rules that apply to transition-aged youth
- to educate the target group concerning their rights under the ADA (Note: We might list here any of the key areas that we listed under section III.B, above.)
- to foster a better working relationship between the BPA&O and the PABSS programs
- to foster a better working relationship between your BPA&O (or PABSS) program and agencies that serve transition-aged youth
- to get more referrals to your BPA&O (or PABSS) program (Note: We could be more specific and state that we want particular types of referrals, noting the types of cases, the characteristics of the beneficiaries, etc.)
- (if you have an existing outreach effort) to increase attendance at training events and bring down the cost of putting on these events

Within any of the listed categories there are many specifics you could list. For example, you might want to focus on one or more of the work incentives, such as a campaign to promote the availability of the Student -Earned Income Exclusion or the Plan for Achieving Self Support (PASS). You might want to promote the availability of VR agency sponsorship for college studies. Or, your purpose in developing a stronger relationship with the school district may be to have benefits planning, through your BPA&O program, a defined part of the transition plan developed by the school.

When setting your goals and objectives, some may be obtainable very quickly and others could take a year or more to reach. Some are totally within your control, while others may or may not be sure things. Be realistic in setting time tables and in determining your scope of work. Set some goals that are within your control and can be accomplished within a specific time frame. For example, a mass mailing of a flyer describing SSI benefits for transition-aged youth is something totally within your control (subject to SSA approval of the flyer's contents) and can be achieved within a matter of months. The results sought from this activity — more knowledge among the target group, more referrals for BPA&O services — are, on the one hand, difficult to measure and, on the other hand, somewhat out of your control. However, by carefully selecting the right partners for this effort, the quality of your mailing list may help ensure a good outcome in terms of referrals.

D. Make a Good List of Where You are Likely to Meet Youth, Their Parents, and Service Providers

Every community will have regular meetings or events that serve as opportunities to meet the target group. For example, in Western New York there is an annual event called Developmental Disabilities (DD) Day that draws hundreds of individuals, including students, parents and service provider personnel from our target group. At this confer-

ence, an agency such as a BPA&O or PABSS program can set up an information table for a small fee and could get selected to present in one of the many workshop slots. At the most recent DD Day conference, our BPA&O program presented a workshop and joined with the PABSS program to staff an informational table.

Any number of groups will exist in your region based on a common characteristic of group members (e.g., parents of special education students, special disability or support groups, or an association of school psychologists). Often, these groups have monthly or quarterly meetings and regularly invite guest speakers. You will need to create an inventory of all such groups, who belongs, when they meet, and what opportunities there are to present at their meetings or distribute informational materials. Simultaneously, you can be adding them to your mailing list as discussed in the next section.

E. Create a Mailing List of Students, Parents, and Service Providers

A good way to approach this is to think of your task as making up a mailing list (or lists) for sending out materials or for publicizing a big conference or other training events. Hopefully, you will have a staff person within your agency or a collaborating agency who has the skills to put this into a database program so that you can later sort for smaller mailing lists according to zip code.

While you should always strive to get students and parents on your mailing list, your mailing list will probably be predominantly made up of individuals who work for agencies (in some cases, these will also be parents of children with disabilities). Remember that the individuals/agencies on your list should be those that work with transition-aged youth. This means you avoid agencies that serve only very young children or only older adults.

Always strive to get actual names and job titles on your mailing list. This makes it more likely that your materials will get to a person who can use the information. Even if that person has left the agency (there is considerable turnover in the human services sector), having the job title in the address will make it more likely that the mail will get to the new person in that job category.

1. Start with Your Existing List of Adult Agencies

Many of these agencies will serve children as well, often through a different division of their program. Here again, it is important to put specific names or job titles on your mailing list. With larger agencies, the children's division may even be at a different address from the adult division.

2. See If Someone Has Already Created a List.

As the saying goes, there is no need to “recreate the wheel”. With a few phone calls to partners or potential partners, there is a very good chance you will find one or more agencies that is willing to share a mailing list, hopefully in an electronic format. Some of

these lists may be over-inclusive — including names of agencies serving only adults or only very young children — but, it is much easier to edit from an existing list than to create your own. With three or four solid lists, your initial mailing list can be put together in a matter of hours and not take several days of your precious time. In the process of soliciting other lists, of course, you are also in a perfect position to begin forging the relationships that might result in partnerships for your big events.

3. Getting Names to Add to the List or to Create Your Own List

The following are some of the key categories of individuals/agencies you will want on your mailing list:

Students and Parents. These may be the hardest names to get. Schools, bound by confidentiality requirements, will not release lists that provide names of children with disabilities. Many other organizations that run programs serving youth with disabilities will face similar confidentiality requirements. Many of the parent or disability-specific organizations, discussed below, may not face legal barriers to releasing names but many will have policies against release of this information.

Two strategies seem to work best in terms of reaching this group. First, you should see if a partner agency — e.g., a school or parent group — might be willing to mail your materials even if they will not disclose names. In some cases you will need to provide postage; in other cases, the agency or association might be willing to insert your materials with other mailings or mail your materials as part of their own outreach efforts. The second strategy is to start your list (and regularly add to it) based on who attends your events. While this is a slow process, over time you will see the list grow and will be one of multiple methods for reaching this part of the target group.

Private Organizations that Serve Parents and Students. The U.S. Department of Education funds “Parent Training Institutes” (PTIs) throughout the country to provide training to parents of children with disabilities. This organization should be on your mailing list and will probably make a good collaborator on your outreach efforts. Similar organizations may be funded by state, local, or private grants.

School Staff and School-Related Organizations. Since you are trying to reach those who work with students with disabilities, you will want to make sure your mailing list includes those school departments and persons within them who are most likely to respond to your communications. This would include personnel involved with special education, vocational programs, and school guidance. This would also include any groups run through the schools for the students themselves or their parents (e.g., many schools with have a PTA for parents of special education students). At the university or community college level, it would include individuals often known as disability services coordinators, i.e., individuals who help locate or arrange for special services and accommodations for students with disabilities.

Disability-Specific Groups. Just open the phone book in any city and you will find any number of agencies that serve persons with disabilities. Using this method to create a mailing list, however, could be a very time-consuming walk through the yellow

pages. A better bet may be to see if your local United Way or some other government or nonprofit group has put together a directory of human services or even disability-specific services in your community, state, or region of the state. You will want to look for some of the typical names (Association for Retarded Citizens, Juvenile Diabetes Association, Down Syndrome Association), but you will also need to look for things by category as there seems to be a trend toward agency names that avoid disability-specific language so that the agency name does little to define their mission.

Membership Organizations. In the author's experience, there are often informal groups that get started by parents and whose members include many parents and even students themselves. These could be centered on a condition or disease such as autism, cancer, or learning disabilities. As you reach out to potential partners for mailing lists, for example, you should ask about the existence of such organizations.

Advocacy Organizations. Every region of the country will have some core advocacy programs that are funded through federal grants, including Centers for Independent Living (CILs), Protection and Advocacy (P&A) programs, and Legal Services/Legal Aid programs. If you are part of one of those programs, do not overlook the possibility that there are persons within your agency who have an overlap with you in terms of the populations they serve. For example, if you are a BPA&O program within a CIL, there may be others in the larger agency who have been involved with the transition-aged population. Similarly, if you are a PABSS program within a P&A office, there may be special education advocates (often in the PADD program) who have already put together mailing lists or can put you in touch with the best partners for your collaborations. Depending on your area, there may be any number of other nonprofit, government, or university/law school-based programs that will be appropriate for your mailing list.

Vocational Rehabilitation (VR) Agencies. Every state will have a state VR agency and many will have a second state VR agency that serves only persons who are legally blind. In light of their mandates to work with the transition-aged population (see section II, above), the state VR agencies will make perfect candidates to get your mailings and even to partner in your outreach efforts. You will want to investigate to see if one or more key staff at the agency are already involved in work with the transition-aged population.

Every good-sized city and many smaller communities will be served by one or more private rehabilitation agencies that run employment and training programs for persons with disabilities. In the author's experience, personnel from those agencies always make up a significant part of the audience at larger events. Also, many of these agencies may want your staff to do presentations at their agency sites.

The Social Security Administration. Key staff within your region's SSA offices should be on your mailing list, including: the Area Work Incentive Coordinator (AWIC), the Work Incentive Liaisons for each office, and the PASS Specialist(s) who cover your region. You will want to talk to the AWIC for your region to find out who else from the agency might be appropriate for your mailing list. SSA, with its internal mandate for outreach, should also make a good partner for your events.

V. Developing Your Plan for Outreach

A. Start with a Design Team or Teams

Your design team should, ideally, include about five to six people. One or two people should be from your agency and the others can come from collaborating agencies. Even if you are the only dedicated staff person on your BPA&O or PABSS program, you should consider recruiting another person within your agency to serve on the design team. For example, if you work with a PABSS program, you might recruit an attorney or advocate working with the PADD program (which is expected to serve transition-aged youth with developmental disabilities). It is possible that you will have a small, two-person design team within your agency to create written materials for a mail and media campaign and a larger, six-person team for designing a full-day conference.

B. Develop and Distribute Written Materials

This could be as simple as a mass mailing to persons/agencies on the mailing list you created. It may be enough to include a cover letter and a brochure that describes your BPA&O or PABSS program. If the BPA&O and PABSS programs are collaborating on the effort (and they should), you can include both program brochures and the mailing costs can be split between the two programs. In the mailing you might also include fact sheets or know-your-rights brochures created by your program or others (e.g., materials created by the SSA). Whatever materials you create and disseminate it is critical to ensure accessibility of those materials. Accessibility can happen on several levels. First, if you are targeting a mailing at 14 year old youth you don't want to write the piece at a grade 12 reading level. When designing formatting and packaging think in the context of what captures a 14 year old youth's attention. Secondly, keep in mind that the functional capacities of your end users will be diverse. For individuals who are blind a colorful written brochure or comic may not catch them—think in terms of how you might make that message accessible to them. How might you possibly produce an audio-cassette that might deliver the same message but for someone who is blind? Always make sure materials are available in alternative formats that are equally as engaging. Finally, a review of your end product by the SSA is not enough. Make sure prior to asking SSA to review your product that you have solicited the input of the end user. A outreach team comprised solely of 35 year old+ adults may not be the best suited to package for a 14-25 year old target market.

Keep in mind that putting too much in the envelope will both drive up your postage costs and make it less likely that the recipient will read the materials you have sent. In Western New York, we try to limit our mailing inserts to no more than two or three pieces. Consider using the U.S. Postal Service's bulk mailing rates to save money on larger mailings. Keep in mind, however, that complying with bulk mailing requirements can drastically increase your labor costs. In Western New York, we often use a service offered by a private rehabilitation agency that employs workers with disabilities, to do our bulk mailings for us. Even after paying a fee for the service we still save money.

C. Using the Print, Radio, and TV Media

Many editors for agency newsletters or small community newspapers are often looking for “filler material” — small articles or announcements that are both a public service and fill up a small corner of a page. Agency newsletters in particular may also be interested in longer pieces, i.e., 1,000 words or more, that either describe your program or describe a benefits or legal rights issue of interest to their readers. Consider creating an electronic folder of various-sized articles that you can routinely send to the editors of newsletters and small newspapers.

Radio and TV, particularly public-access cable, offer a unique opportunity for your youth outreach campaign. Typically, commercial TV is best suited to the short, 15 and 30-second public service announcements that you can use to publicize your program or an upcoming training event. Radio and public-access cable can offer opportunities to appear on a variety of public service programs. For example, in Western New York, our BPA&O staff have appeared on a cable TV program to discuss our project and the Social Security work incentives.

D. In-Person Presentations at Events Planned by Others

Presentations at conferences put on by others can be a very cost-efficient way to meet your outreach goals or part of them. In many cases, you will find the same conference occurs year after year with predictable attendance from a group that includes persons you want to reach. Since your potential presentations — e.g., SSI/SSDI work incentives for the BPA&O, ADA issues for the PABSS — can be viewed as hot topics, the conference planners may jump at the chance to have you present.

The group planning the event does all the planning, publicity, registration, and on-site operations; your staff only has to show up and do its presentation. Sometimes the group running the event will cover copying costs of your handouts. In New York, for example, our BPA&O staff have appeared at statewide events run by an association of supported employment providers, a mental health advocacy group, and a self-advocacy association, with repeat performances planned this year at the first two events. Our colleagues at a Minnesota BPA&O report that by employing this strategy, or the alternative of co-sponsoring events, they were able to ensure much better attendance at their sessions that focused on transition-aged youth (see V.F.2, below).

E. Staffing an Information Table at Events Planned by Others

Many of the local, regional, and statewide conferences that are run by others will offer agencies like yours the opportunity to set up an informational table for persons attending its conference. In some cases, there will be a fee for setting up the table. In other cases, the table may be complimentary. You may be able to do one or more presentations at the conference and set up the information table. The table is a place to display information about your BPA&O or PABSS program, to hand out informational materials, and to answer brief questions from persons attending the conference. You can put out a sign-up sheet to offer individuals the opportunity to sign up for your mailing list.

F. Planning Your Own Outreach / Education Campaign Events

I. Putting On a Full-Day Conference - the Western New York BPA&O Experience

Running a full-day event for a large group may seem like a daunting task. It gets easier when you divide it into a number of smaller tasks and some of the work is spread out among a group of collaborators. The conference described here has been delivered by the Western New York BPA&O three different times, with attendance totaling 450 persons for the three conferences. Summarized below are some of the key elements that have gone into making this a success.

Design team. The original design team and conference grew out of a group that got together to discuss ways to collaborate in an effort to reach transition-aged youth. The team included the Western New York BPA&O and PABSS programs director, a BPA&O benefits specialist who coordinates many of their training sessions, a person who coordinates employment programs for a disability service organization, a person who oversees a job placement program for youth with disabilities through a consortium of agencies, and the Director of Training for a small agency that provides training and a resource center for parents of youth with disabilities.

Co-Sponsors. On the promotional materials the BPA&O agency was listed as the primary sponsor of the event with our co-sponsors listed separately in alphabetical order. Co-sponsors included: the design team agencies (Parent Network, Aspire, and the Bridges to Employment Program), the Social Security Administration, the Western New York Transition Coordination Site, the state VR agency and state VR agency serving the blind, the Regional Rehabilitation and Counseling Education Program (RRCEP II), and the state's Developmental Disabilities Planning Council. The co-sponsors provided funding or in-kind support to cover all or part of the cost of: postage for mailing, speaker's fee, refreshments, parent/student scholarships, school personnel scholarships, sign language interpreters, handout folders, and secondary distribution of conference flyers at other events. As the lead sponsor, the BPA&O arranged for printing of the flyer, mailing lists, mailing, pre-registration, on-site registration, conference-related billing, relationship with co-sponsors, and tabulating conference evaluations.

Design of the Conference. The original conference was designed to run from 8:45 a.m. to 3:15 with one hour for lunch. It was later expanded to end at 3:45 to allow afternoon sessions to run for 75 minutes rather than 60 minutes. The design team settled on an agenda that both met the needs of the target audience and took advantage of local/regional training expertise, most of which could be obtained without a fee.

Increased referrals resulting from activity. It is clear that calls to the BPA&O from the target group (students, parents, and service providers) have increased as a result of the three conferences. One immediate benefit is that the Western NYS BPA&O now gets considerably more calls from service providers (including school programs) to give presentations related to SSI and transition-aged youth. Even some of

the co-sponsors, having embraced the importance of the BPA&O services, are now referring more youth with disabilities to the BPA&O Program. While the number of new benefits planning cases for youth with disabilities is fairly low, with probably no more than 20 to 25 new cases attributable to these three conferences, the project is confident that a continuing influx of new cases will come if they continue to sponsor this large conference at least once per year.

2 Doing a Series of Smaller Sessions Throughout a State or Region of the State — the Minnesota Experience

The Minnesota Work Incentives Connection, a BPA&O program in St. Paul, Minnesota, provides BPA&O services in a 70-county region of Minnesota. The Work Incentives Connection undertook an intensive three-year initiative to reach out to parents and transition-aged youth with disabilities. They did this primarily through a subcontract awarded to the Minnesota Disability Law Center, through its parent agency, the Legal Aid Society of Minneapolis. This summary was prepared after communications with both Barb Smith of the BPA&O program¹⁸ and Jennifer Giesen of the Disability Law Center (DLC). Ms. Giesen is an attorney, who works on P&A grants (other than PABSS), and was one of the primary trainers on this project.¹⁹ The other primary trainer was Linda Bonney, a legal advocate with the DLC.

During this three-year period, 61 different sessions were presented: 24 in year one, 20 in year two, and 17 in year three. During year two, the sessions were co-presented by Ms. Giesen and BPA&O staff. During years one and three, DLC staff were the only trainers. The sessions were designed to last approximately two hours, mostly on evenings or weekends, and focused on the following areas: the special education transition planning requirements, focusing on the area of employment; the state VR agency and how to plan for their involvement; a primer on SSI and SSDI; an overview of the work incentives; and a description of the services provided by the Work Incentives Connection. The content of the work incentives component varied somewhat from audience to audience. The level of detail about SSI, SSDI, and the work incentives depended on the familiarity of the audience with these topics. Sessions were at no charge to those attending.

Ms. Giesen reported that the biggest challenge during year one of this project was low attendance at many of the sessions. Recognizing their ability to recruit people to attend the sessions was dependent on using the network of consumer and parent organizations present in the state, the DLC's approach to organizing the sessions during years two and three was very different. First, they identified numerous conferences that were already taking place in a location which would attract their target audience. Second, where a region had no conferences scheduled, they would contact a service provider and inquire about their willingness to co-sponsor a training program. Using these approaches, attendance went up significantly, with approximately 1,000 individuals attending during the last two years (an average of about 25 per session). About 70 percent of those attending were either parents or students, with an even higher rate of parental attendance in some rural areas, representing a very successful outreach effort to this group.

¹⁸Barb Smith's contact information is 651-632-5108 or barsmith@ngwmail.des.state.mn.us.

¹⁹Jennifer Giesen's contact information is 612-746-3714 or jgiesen@midmlegal.org.

Barb Smith reported that actual case referrals from this very successful activity were fairly low, with benefits planning cases for this Minnesota BPA&O program still in the range of 15 or so. Her observation was that many parents of youth with disabilities were still struggling with making sure that appropriate special education services are in place and that getting parents to recognize the importance of SSI and the work incentives, as part of transition planning, remains a continuing challenge.


3. Taking Your Outreach Team Directly to the Schools—the Brooklyn Works Experience

Brooklyn Works, a BPA&O program serving the New York City borough of Brooklyn, used a face-to-face approach with the schools and related programs to reach out to the transition-aged population. This provided the BPA&O staff with one-on-one and small group contact with building administration, individual teachers, and students. This approach represents an example of basing the outreach plan on the realities of geography and population density. While the Minnesota program faced the challenge of traveling to small town and rural areas hundreds of miles from their primary office, the Brooklyn program was able to reach hundreds of their target audience group by taking a number of subway rides. Based on the number of benefits planning files the Brooklyn program has opened to serve transition-aged youth, 70 case files as this is written, this approach can be categorized as a great success. This summary was prepared after communications with Olga Ivnitsky of the BPA&O program²⁰ and is based on the joint efforts of Ms. Ivnitsky, who also runs the program, and Linda Speaker, who has lead the effort in reaching out to the target groups.²¹ Ms. Speaker has spent nearly all of her time on issues related to transition-aged youth.

One of the early steps in this effort was to contact the Board of Education which, in turn, leads to a connection with the Transition Linkage Coordinators. Learning that the group of coordinators had regular meetings, the BPA&O staff arranged to make a presentation at a group meeting to explain the services of their program. In doing so, they were able to also engage some Linkage Coordinators in informal conversation and collect names and phone numbers of the entire group.

The BPA&O staff also arranged to go out to all of the Brooklyn high schools. They were introduced to building principals, guidance counselors, and special education teachers, with each introduction serving as an opportunity to explain the BPA&O's services and hand out materials. Linda Speaker even managed to get invited to some special education classes where she explained the BPA&O project to students. BPA&O staff was also invited to attend some parent/teacher conferences.

Another component of the Brooklyn Works outreach plan was to connect with what is known as District 75, which oversees full schools devoted to special education instruction. In reaching out to these schools, the BPA&O staff went to a district-wide staff meeting and spoke to the group. By doing that, they managed to get invitations to speak at the various schools. Once again, the ultimate goal was to reach the transition-aged student which they did on many occasions.

²⁰Olga Ivnitsky's contact information is 718-368-7923 or olga.ivnitsky@labor.state.ny.us.

²¹Linda Speaker's contact information is 718-368-7923 or linda.speaker@labor.state.ny.us.

Additional outreach was done through the Young Adult Institute, an agency that had recently been approved as an employment network under the Ticket to Work program. BPA&O staff went to this agency and talked to both staff and the youth being served by them. One area of focus was to explain how students in a summer work program could take advantage of SSI's student earned income exclusion.

Of the three outreach efforts discussed in this article, the Brooklyn Works initiative is by far the most intensive. Its success was, in part, dependent on the ability to reach large number of special education personnel and students within some very large programs.

VI. Conclusion

This policy and practice brief has provided readers with a resource to guide their efforts in providing outreach to transition-aged youth, their parents, and service provider agencies. In planning your own outreach programs, readers are urged to carefully consider the organizational strategies outlined and the three different approaches used by BPA&O programs in Minnesota, Western New York, and Brooklyn. In the end, your outreach program will work best with solid planning that recognizes your existing strengths, the strengths of your collaborators, and the unique characteristics of your geographic region and the population you wish to reach.

One final note is that readers from BPA&O and PABSS programs should be willing to look at outreach to transition-aged youth as a multi-year initiative, with success expected to come in a modest number of new referrals. When you work with adults and adult service providers, there is significant knowledge of the importance that SSI, SSDI, and Medicaid play in the lives of adults with severe disabilities and a growing recognition of the need for more knowledge about the work incentives. By contrast, with parents and youth service providers the knowledge gap is much more significant. Before our target audience can be expected to fully embrace the importance of benefits planning as part of transition, our outreach efforts must first bridge the basic knowledge gaps about the future role that SSI and SSDI will play in the lives of these young adults. Only then will the availability of the BPA&O's benefits planning services become important to them.

MY NOTES ON TRANSLATING THIS TO PRACTICE:

MY STATE CONTACTS:

Contact Information

Employment and Disability Institute School of Industrial and Labor Relations

Cornell University
ILR Extension Bldg., Rm. 201
Ithaca, New York 14853-3901
607/255-7727 (voice)
607/255-2891 (TTY)
607/255-2763 (fax)
ilr_edi@cornell.edu (e-mail)
www.edi.cornell.edu

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