DOCUMENT RESUME

ED 465 234 EC 308 990

AUTHOR	Petroff, Jerry G.
TITLE	National Transition Follow-Up Study of Youth Identified as Deafblind: Parent Perspectives. NTAC Briefing Paper.
INSTITUTION	National Technical Assistance Consortium for Children and Young Adults Who Are Deaf-Blind, Monmouth, OR.
SPONS AGENCY	Special Education Programs (ED/OSERS), Washington, DC.
PUB DATE	2001-08-00
NOTE	30p.
CONTRACT	HO25C60001
AVAILABLE FROM	DB-LINK, The National Information Clearinghouse on Children Who Are Deaf-Blind, 345 N. Monmouth Ave., Monmouth, OR 97361. Tel: 800-438-9376 (Toll Free); TTY: 800-854-7013 (Toll Free); Fax: 503-838-8150; e-mail: dblink@tr.wou.edu. For full text: http://www.tr.wou.edu/ntac/pdf/transition.pdf.
PUB TYPE	Reports - Descriptive (141)
EDRS PRICE	MF01/PC02 Plus Postage.
DESCRIPTORS	Basic Skills; Community Programs; *Deaf Blind; *Education Work Relationship; Followup Studies; Graduate Surveys; High Schools; Literacy Education; *Parent Attitudes; Quality of Life; Student Experience; Student Needs; *Transitional Programs; Work Experience Programs

ABSTRACT

This study surveyed the parents/guardians of 97 youth (ages 18-24) throughout the United States who are deaf-blind and who left school in June 1996. The survey was conducted 18 months after these youth had left school. Following an introduction, this report first presents findings related to characteristics of the youth in the areas of communication, reading, mobility, health, and behavior. The next section presents data on secondary school experiences including last educational placement, related services, work experience in secondary education, and planning for transition. The section on post-school life addresses further education, support services, community involvement, living arrangements, and employment. The final two sections provide information on parental satisfaction, consider implications of the study, and offer recommendations. Among these seven recommendations are the need to provide services that promote communication development, that promote the development of literacy, that provide for education with nondisabled peers, that offer real job experience with community-based vocational training, and that provide person-centered transition planning beginning no later than age 14. (Contains 75 references.) (DB)

NTAC

Briefing Paper

National Transition Follow-Up Study of Youth Identified as Deafblind: Parent Perspectives

Jerry G. Petroff, Ph.D.

Published August 2001 by:

NTAC *The National Technical Assistance Consortium for Children and Young Adults Who Are Deaf-Blind*

NTAC
Teaching Research
345 N. Monmouth, Ave
Monmouth, OR 97361
Ph. 503.838.8757
TTY: 503.838.9623
Fax: 503.838.8150
ntac@wou.edu

NTAC
Helen Keller National Center
111 Middle Neck Rd.
Sands Point, NY 11050
Ph: 516.944.8900 x307
TTY: 516.883.9059
Fax: 516.883.9060

To request copies of this document, visit http://www.tr.wou.edu/NTAC or contact:

DB-LINK - The National Information Clearinghouse on Children Who Are Deaf-Blind
345 N. Monmouth, Ave
Monmouth, OR 97361
Voice: 800.438.9376
TTY: 800.854.7013
Fax: 503.838.8150
dblink@tr.wou.edu

IDEAs that Work
Office of Special Education Programs

This Project (grant number HO25C60001) is supported by the US Department of Education, Office of Special Education Programs (OSEP). Opinions expressed herein are those of the authors and do not necessarily represent the position of the US Department of Education.

Contents

Introduction

Historically youth who are deaf-blind have not had the supports that are necessary for success in adult life. *The National Transition Follow-Up Study of Youth Identified as Deafblind: Parent Perspectives* (Petroff, 1999) found that many youth who are deaf-blind have not been provided with the type or quality of education that generally yields successful outcomes in employment, independent living, and community involvement. The study revealed that upon leaving high school, these young people may expect that:

- They will not go on to participate in post-secondary education.
- They will experience high rates of unemployment and underemployment.
- They will probably not live independently.
- Their repertoire of experiences in community life will be limited.
- They will create few close relationships (other than with family members).

Of all students with disabilities, only a small number have both vision and hearing impairments. Estimates indicate that only two out of every thousand students receiving special education services are deaf-blind (Baldwin, 1993). Members of this low-incidence group are extremely diverse in their abilities, supports, and needs. These factors contribute to the difficulty of gathering reliable and detailed descriptive information, especially as it relates to post-school status. Past attempts (e.g., the National Longitudinal Transition Study) to gain an impression of the specific characteristics and status of individuals with deaf-blindness have been to no avail (Blackorby & Wagner, 1996; Wagner, 1993; Wagner, Newman, & Shaver, 1989).

The National Transition Follow-Up Study of Youth Identified as Deafblind: Parent Perspectives (Petroff, 1999) is the first research initiative to thoroughly explore the post-school life of youth who are deaf-blind. Besides gathering demographic information, the study sought information regarding the diverse characteristics of youth who are deaf-blind regarding communication, sensory status, mobility, health, and problem behaviors. It also explored secondary school experiences, especially regarding services and supports, work experience, and transition planning. Parents were asked about post-secondary experiences, education, employment, living arrangements, and community involvement. And finally, they were asked about their satisfaction with current and past services and support.

This study was designed to survey the parents/guardians of youth who are deaf-blind who left school in June 1996. The survey was conducted 18 months after these youth had left school. Their ages ranged from 18 to 24. The survey contained 86 items arranged under four general areas of inquiry: family demographics, characteristics, past school experience, and post-school life. With the assistance of the Helen Keller National Center and the National Technical Assistance Consortium of Children and Youth who are Deaf-Blind (NTAC), surveys were distributed to each of the states' federally funded deaf-blind technical assistance projects. In keeping with the guidelines for confidentiality, surveys were distributed to families by the individual state deaf-blind projects, returned anonymously to NTAC, and then forwarded to the researcher. The state project distributed the surveys to the identified families.

The state projects reported an estimated total of 204 youth who left school in June of 1996. The number of surveys returned (102) was 44.35% of the total population and the number of surveys used in this research (97) represents 42.17% (see Table 1 for demographics).

Table 1. Demographics

Race/Ethnicity of Youth (N=97)		**Type of Community (N=97)**	
Native American	3%	Suburban	43%
African-American	10%	Rural	37%
Hispanic	10%	Urban	20%
Caucasian	74%		
Other	3%		

Characteristics of Youth who are Deaf-Blind

This study showed remarkable diversity in communication development, mobility, and presence of challenging behavior. One important finding was that a high percentage of youth use gestures, vocalizations, facial expressions, and/or behaviors as their primary mode of communication. The number of youth who use sign language was surprisingly low. Additionally, although the majority were nonreaders, those with literacy skills performed at a reading level of fourth grade or above.

Limitations of the Study

Although the survey method is recognized as an important and valuable tool compatible with the purposes of this study, it has certain limitations. The most fundamental limitation is the constraint of addressing complex inquiries with a limited number of survey questions. Questions need to be formulated that yield information relative to specific research questions. A finite number of items are developed to yield just enough data to adequately address each research question. Another restriction of the survey method is its inability to use results for the purposes of drawing quantitative forecasts of the future.

Despite the precautions taken in this study to ensure that the procedures conducted were reliable and the

Although these findings validate general impressions of youth who are deaf-blind, they expand upon previous literature (Baldwin, 1991; Everson, 1995; Fredericks & Baldwin, 1987; Haring & Romer, 1995; Riggio, 1992) by providing more comprehensive national data regarding the diversity. The data from this study support earlier findings, but further suggest that these individuals may not be evenly distributed across any continuum of functioning. In fact, a close analysis of the data shows that the majority of youth who are deaf-blind are divided into two very different categories: (a) youth who do not communicate with language (signed or spoken, 49.5%) and also do not walk conclusions drawn were valid, certain limitations apply to any generalizations of findings. This study was designed and conducted to obtain the status of a specific population of young adults at a specific point in time. Therefore, no attempt should be made to generalize the results. The value of the results is reflected in the overall composite they provide of recent school leavers who are deaf-blind. In addition, impressions about the diversity of the entire population are articulated, which may or may not reflect the characteristics of any one individual.

Lastly, the interpretation of the results of this study must be viewed in its appropriate context. This research was conducted from the perspectives of parents who are a reliable source of the kind of information sought by this study. However, their responses are based on judgments, recollections, and perceptions. Their views are naturally influenced by their emotional and psychological involvement with their children.

independently (44%), and (b) youth who communicate primarily using spoken and/or sign language 49.5% and also walk independently (56%). This sharp distinction between two majority groups within this population has not been clearly reported in the past. An analysis of the data regarding communicative function, reading ability, and mobility results in a profile of these two majority constituencies that may require two very different kinds of educational and post-educational experiences and support.

Communication

Although a few authors suggest that individuals who are deaf-blind communicate in a variety of ways (Welch & Huebner, 1995), there has been no indication of the extent to which they communicate using nonsymbolic methods. There does appear to be an impression that those individuals who are deaf-blind and have additional disabilities that would affect the development of language are only "one small segment of people who are deaf-blind" (Collins, 1993, p.141). The findings of this study suggest that fully one half of the youth do not use symbolic communication (see Table 2). This may be explained as either (a) the concomitant effects of multiple disabilities preventing the development of language or (b) language-based communication systems have not been taught or have not been made available to these youth (Gothelf & Brown, 1996). The survey was designed with the assumption that all youth demonstrate some form of communication; therefore, parents were not given the opportunity to respond that their children did not have any method of communication at all.

Table 2. Primary Method of Communication

Communication Method	**N=97**	**Number of Expressive Words**		
		150+	**50-100**	**<50**
Nonsymbolic	50%	▨	▨	▨
Speech (symbolic)	32%	72.5%	7.5%	20%
Sign Language (symbolic)	18%	35%	28%	37%

The wide range of communicative functioning of individuals who are deaf-blind to include the use of spoken language has been documented (Rowland, 1987; Rowland, Schweigert, & Stremel, 1992; Stremel, 1991; Stremel & Schutz, 1995). However, indications of the frequency of speech usage did not approach those of this study. Issues of communication for individuals who are deaf-blind focus on either early communication training (Huebner, Prickett, Welch & Joffee, 1995; Rowland, Schweigert & Stremel, 1992; Stremel, 1991; Van Dijk, 1967) or augmentative communication systems (Rowland, 1987; Strong et al., 1993). Despite the number of youth who use speech as a primary form of communication, a review of current literature shows very little information, research, and emphasis on the promotion/training of speech skills for youth who are deaf-blind.

The data from this study suggest that sign language may be used most often in conjunction with other modes of communication, serving as an augmentative rather than primary system (Table 3). Individuals who are considered culturally deaf (Collins, 1995) and have no additional disabilities are likely to be included as the 18% of those who use sign language as a primary mode of communication.

Table 3. Modes of Communication

Types of Communication	**Expressive (All that apply)**	**Receptive (All that apply)**	**Primary (One)**
Spoken language	36.1%	69.1%	31.6%
Sign language (visual)	27.8%	29.9%	16.8%
Sign language (tactile)	09.3%	12.4%	01.1%
Gestures, vocalizations, etc.	68.0%	56.7%	49.5%
Electronic picture/symbol system	05.2%	03.1%	01.1%
Writing/Braille	12.4%	09.3%	0
Pictures/objects	13.4%	15.5%	0
Valid cases	97	97	95

Reading

In an attempt to gain insight into the academic abilities of youth who are deaf-blind, the respondents were asked to describe their child's reading ability. Once again the population seemed to be divided between two very different subgroups (Table 4). Little or no information has been previously published regarding reading and academic abilities in deaf-blind youth.

Table 4. Reading Ability (N=94)

Nonreaders	62%
Reading above a 4th grade level	27%

Mobility

The results of this study regarding mobility further demonstrate that a large subgroup of youth who are deaf-blind have additional disabilities. Campbell (1995) states that these youth are more likely to have motor impairment as a result of central nervous system dysfunction than as an artifact of their sensory impairment. These data suggest that other motor involvement may negatively affect the youths' ability to utilize language systems based on speech and/or sign.

Table 5. Mobility (N=94)

Walks independently	56%
Not independently mobile	43%
Uses wheelchair but is independently mobile	1%

Health

In order to expand the understanding of the diversity of this low-incidence population, the study obtained descriptive information regarding health and adaptive behavior. The vast majority of youth were reported to have fair to excellent health (see Table 6). There is no indication that individuals who are deaf-blind will have significant health care needs. However, it has been reported that when visual and auditory impairments are related to central nervous system damage, medical problems may also be present (Campbell, 1995). Many causes of deaf-blindness include associated medical and health concerns (Boys' Town National Research Hospital, 1990; O'Donnell, 1991; Wolf-Schein, 1989). The results of this study indicate that if medical problems are present, the majority are being managed effectively (Table 7 and Table 8). This study focused on individuals in the late teenage years; it may be that health problems are more of an issue in early childhood.

Table 6. General Health (N=94)

Fair	59%
Excellent	36%
Poor	5%

Table 7. Medication (N=95)

Purpose of Medication	Percent
Mood, anxiety, sleep, or behavior	34%
Seizure control	57%
Other health-related problem	55%
Total	73%

Table 8. (N=93)

Seizure Activity	Percent
Weekly/or more often	15%
Monthly	5%
Less than monthly	9%
Total	29%

Behavior

Many individuals who are deaf-blind engage in problematic or challenging behaviors which often begin early in life (Mar, 1992). Since there is a recognized correlation between behavior and communication (Carr & Durand, 1985; Durand, 1990), it is not surprising that individuals who are deaf-blind present difficulties in this area (Crimmins et al., 1995). Over half of the respondents reported that their children engaged sometimes or frequently in unusual or repetitive habits (Table 9). This is not remarkable since the absence of or diminished sensory functioning increases the need for stimulation and often results in the development of self-stimulatory behavior (Choss & Fernandez, 1980; Haring & Romer, 1995). Socially offensive behavior is reported as the next most frequent type of behavior. This is not surprising. The development of appropriate social behavior is often learned through the distance senses by modeling the behavior of others. The majority of respondents indicated that their child sometimes engaged in hurtful self-injurious, aggressive, or destructive behavior.

Table 9. Behavior (N=95)

Behavior	Percent
Unusual or repetitive habits	39%
Socially offensive behavior	38%
Hurtful to self	35%
Hurtful to others	27%
Destructive to property	19%

Given that problematic behavior among students who are deaf-blind has been reported previously (Crimmins et. al., 1995; Everson, 1995; Frey, 1988; Gothelf, Rikhye & Silberman, 1988; Goetz, 1993; Haring & Romer, 1996) and the known link between communication and the incidence of challenging behavior, it was surprising that reported levels were not higher.

Past School Experience (Secondary Education)

With the exception of deaf-blindness, data exist for nearly all disabilities regarding the nature of a young adult's exit from school (Wagner, 1993). The present study shows that youth who are deaf-blind seem to depart from the pattern of students with other disabilities in regards to the manner in which they left school (Table 10). Students with deaf-blindness are more likely to remain in school through age 20.

Table 10. Comparison of Manner of Leaving School

	Youth w/deaf-blindness (N=97)	Youth w/disabilities[1]
Age out	50%	8%
Graduate w/diploma	47%	59%
Drop out	3%	33%

The data show that students who are deaf-blind, regardless of need, remain in school until they no longer are entitled to a public education. One would expect that completion of a free and appropriate public education should be linked to successful adult outcomes. Given that students who are deaf-blind are more likely to remain in school until the maximum age, one would expect successful outcomes in employment, independent functioning, and community integration. The results of this study do not support these expectations.

---

[1] *NLTS (National Longitudinal Transition Study, 1996)*

Last Educational Placement

Students who are deaf-blind are currently educated in a variety of settings across a continuum from least to most restrictive environments (Baldwin, 1992). The findings of this study corroborate this impression while providing further detail about the nature of educational placements (Table 11).

Table 11. Secondary Educational Placement (N=93)

Segregated special education		82%
Special education/Self-contained in gen. ed.	26%	
Special education/Separate school	28%	
Special vocational education/Separate school	11%	
Other	17%	
General education settings		18%

With an increasing emphasis on the importance and benefits of educating all students in inclusive regular educational settings (Ford & Fredericks, 1995; Stainback & Stainback, 1995; Villa & Thousand, 1992), these results are noteworthy. It appears that students who are deaf-blind are among those who continue to be segregated despite legal mandates, research, and practices that support inclusion within our schools and communities. The continued separation of this group during school will only lead to their continued separation and isolation in adult life. However, the 18% of youth educated in regular education settings shows a favorable increase from the past

Related Services

It is often assumed that students who are deaf-blind require an elevated number of related services to address their specialized educational needs (Huebner et al., 1995; Reiman & Johnson, 1993). In the absence of prior existing data, the results of this study describe and quantify this issue. From a list of 15 related services frequently used by students with disabilities, respondents were asked to identify all the services their child received during his/her last year of school (Table 12).

Communication. Sixty percent of the youth received speech and language services. This appears remarkably low for this population. The significant impact of hearing and vision loss on the development of language and communication would appear to necessitate support in this area throughout a student's educational career regardless of the level of functioning (Prickett, 1995; Rowland, 1987; Stremel, 1991). Communication is central to the education of students who are deaf-blind (Ford & Fredericks, 1995; Stremel & Schutz, 1995).

Orientation and Mobility. Considering that approximately 50% of the youth ambulate on their own (Table 5) and have significant enough sensory impairment to be considered deaf-blind, one would think that the rate of orientation and mobility services should be even higher (see Table 12, f). The low level of orientation and mobility services may be due to the fact that educational programs do not routinely provide this type of support to students with severe disabilities (Gee, Harrell, & Rosenburg, 1987), despite the necessity of effective orientation and mobility skills for optimal independence.

Support. Twenty-five percent had a single dedicated support person with them at all times. It is striking that 80% of the students are in segregated programs, yet 25% still required and had the benefit of one-to-one support.

Table 12. Related Services/Final School Year (N=97)

a. Speech and language therapy services	60%
b. Physical therapy	45%
c. Vision education services/Teacher of the blind/vi	42%
d. Occupational therapy services	41%
e. Hearing education services/Teacher of the deaf	32%
f. Orientation and mobility training	31%
g. Audiological services	30%
h. Social work services/Support	29%
i. Vocational rehabilitation services/Consult	29%
j. Intervener/1 to 1 teacher's aide	25%
k. Job coach support	21%
l. Personal care attendant	20%
m. Nursing services	17%
n. Sign language interpreter	17%
o. Personal counseling or therapy	8%

Work Experience in Secondary Education

The positive influence of secondary educational work experiences for students with disabilities is well documented (Cobb & Neubert, 1992; Johnson & Rusch, 1993; McDonnell, Ferguson, & Mathot-Buckner, 1992; Wehman & Hill, 1980; Wehman, 1981; Wehman, Kregel, & Barcus, 1985). If the goal of education is to prepare students to achieve optimal independence and to function as contributing members of their communities, then it seems logical to provide an education rich with real-life work experiences. Best practice in secondary education indicates that students with disabilities, including those with deaf-blindness, must have real work experiences (Everson, 1995; Falvey, 1986; Nisbet, 1992). This training should begin during the student's primary education and be systematically expanded (Brown et al., 1979; Nisbet, 1992; Wehman, 1985).

An extremely low percentage of youth were found to have had an opportunity for vocational instruction and real work experience in the community (Table 13). It is difficult to expect that a student who is deaf-blind will function independently and productively in adult life without prior instruction in real-life settings when so many (32%) are not provided with relevant community working experiences. Students who are successful in obtaining and maintaining paid work in community settings following high school are those who received ongoing opportunities for training in community employment sites throughout their high school careers and who obtained paid employment before graduation (McDonnel et al., 1992).

Table 13. Vocationally Oriented Program/Work Experiences (N=93)

Not in a vocational program	32%
Classroom setting (simulated work experiences)	20%
Community-based instruction	12%
Competitive/Supported employment experiences	8%
Sheltered employment experiences	5%

Apparently real work for real pay is not being considered as a possible outcome for the majority of youth who are deaf-blind. Most are either not in vocational programs or are participating only in classroom activities or sheltered employment settings. Only 8% of the youth were reported as having competitive or supported employment experiences as a component of their secondary education. Even adding those youth reported as having community-based instructional experiences, the number of youth remains well under one quarter of those surveyed.

Planning for Transition

In 1990, amendments to the Individual with Disabilities Education Act mandated that schools address transition from school to adult life within the student's Individual Education Plan (IEP) starting at age 16. Depending upon whether the student is graduating with his or her nondisabled peers, transition planning should occur from 2 to 5 years prior to leaving school. This present study indicates that the vast majority of youth who are deaf-blind leave school at the maximum age of 21 (Table 14). Therefore, for most students who are deaf-blind, transition planning would be expected to occur for at least 5 years. A minimum of 4 years of formal transition planning is needed to realize successful outcomes for student with disabilities (Halpern, 1993; O'Leary, 1992; Romer & Romer, 1995; Wehman, Moon, Everson, Wood, & Barcus, 1987; Wehman, Moon, & McCarthy, 1987).

Table 14. Transition Planning (N=95)

No written transition plan	40%
Engaged in transition planning < 1 year prior to graduation	33%
Never engaged in formal transition planning	23%
Engaged in transition planning - 2 years	23%

Despite mandates in federal regulations, the majority of students in this study did not receive adequate transition planning. These results raise serious concerns regarding current educational practices for youth who are deaf-blind since there is a strong correlation between comprehensive, longitudinal transition planning and successful transition to adult life (O'Leary, 1992; Wehman et al., 1985).

Best Practices in Transition Planning. Planning for the future for a student with a disability is a complex process in which traditional educational planning vehicles often are not sufficient (Mount & Zwernik, 1988; Nisbet & Hagner, 1987; O'Brien, 1987). Transition planning must include methods that focus on the students' and their families' visions of the future and do not rely solely on the judgment of professionals. A minority of students in this study participated in these types of activities (Table 15).

Interests and Preferences. Identification of the interests and preferences of students and their parents is a crucial part of the transition planning process (Mount, 1992; O'Brien, 1987). It is difficult to develop a plan for any student's future without authentic input from the individual and his or her family. Only 40% of the students' and/or parents' interests and preferences were identified as a component of the transition-planning process (Table 15).

Table 15. Activities that Occurred in the Transition-Planning Process (N=97)

Discussion at IEP meetings	78%
Additional planning meetings	40%
Identified students' interest/preferences	40%
Identified Parents' interest/preferences	40%
Parent training in transition	18%
Person-centered planning	12%
Local/Community team task forces	10%

Person-Centered Planning. Person-centered planning refers to the use of a process tool to gather information and clarify a path for an individual's future by documenting relevant background, experiences, preferences, current life situation, and other important variables (Forest & Pearpoint, 1990). Person-centered planning departs from developing a plan for an individual that is rooted in what the system can or is willing to provide (Mount, 1992). Only 12% of youth and their families in this study were involved in person-centered planning. Findings of this study show a dramatic need for high quality transition planning based on a person-centered approach that yields relevant individual outcomes.

Post-School Life

Further Education

There are increasing opportunities for youth with disabilities to pursue education after high school (Blackorby & Wagner, 1996; Chadsey-Rusch & O'Reilly, 1992). These opportunities include regular and special programs within 4-year colleges, community colleges, technical schools, and a variety of vocational rehabilitation programs (Table 16). Seventeen percent of the youth in this study attended post-secondary educational programs within 2 years of exiting from high school. None attended a 4-year college.

Table 16. Post-Secondary Education (N=93)

Attended a vocational rehabilitation program	8
Attended community college	5
Attended a vocational/technical school	2
Attended adult school	1
Attended a 4-year college	0

This study asked the parents of those youth who were not currently participating in a post-secondary program, if they had any plans for the youth to attend a program within the next year. Of the 14% affirmed plans for attending a post-secondary program, the majority indicated that they expected their child to attend a vocational rehabilitation program. This suggests that these individuals were waiting for a placement in an vocational rehabilitation program such as the Helen Keller National Center, Sands Point, New York.

Support Services

It is widely recognized that individuals with deaf-blindness require a variety of ongoing support services to gain access to and maximize their participation in the community (Everson, 1995; Reiman & Johnson, 1992; Watson & Taft-Watson, 1993). The majority of young adults who are deaf-blind are not provided with the types of adult support services necessary to achieve optimal independence and quality of life (Perreault, 1993; Watson & Taft-Watson, 1993).

This study attempted to describe the types of adult services being provided for young adults who are deaf-blind (Table 17). Although the results were varied, some overall conclusions can be drawn about the total population.

Service Coordination. Coordination of the various services is important for children who are deaf-blind (Everson, Burwell, & Killam, 1995; Frey, 1988). The majority of respondents reported that service coordination was needed and was being provided (Table 17, c). The complexity of the effects of deaf-blindness, combined with a lack of trained deaf-blind specialists, often results in the provision of an elevated number of services (Best, 1992; Riggio, 1993) to support the educational and adult needs of these individuals. To substitute for the support of one professional specializing in deaf-blindness, an array of support services are provided.

Community Involvement. These findings corroborate the overall impressions previously reported regarding the level and quality of community involvement of youth who are deaf-blind (Table 17, a,g,k). Direct intervention and appropriate support may be required for individuals who are deaf-blind so they may access the community and its members.

Communication and Language. The identified need for continued communication and language services (Table 17, m) may indicate that many youth are leaving school without formal communication systems and skills. It may, however, also reflect the fact that communication and language abilities continue to develop throughout life. According to this survey, these services are inadequate. Their lack may adversely affect the ability of deaf-blind youth to pursue a successful adult life.

Transportation. Lack of transportation often prevents an individual with a disability, specifically deaf-blindness, from engaging in employment or accessing community services (Everson, 1995; Haring & Lovett, 1990; Hasazi, Gordon, & Roe, 1985). Only one-fifth of the respondents identified transportation as a support service that is needed but not provided (Table 17, d,f). However, it should be noted that if these youth don't have jobs or places to go, then transportation is not an issue.

Table 17. Needed Support Services (N=97)

Support Services	Provided and Needed	Provided and Not Needed	Not Provided and Needed
a. Income assistance	83%	2%	8%
b. Medical/Dental services	74%	3%	11%
c. Service coordination	73%	6%	9%
d. Transportation/Daily	63%	2%	20%
e. Med. equip., supplies, medicines	58%	3%	12%
f. Transportation/Non daily	48%	2%	27%
g. Personal assistance services	48%	2%	20%
h. Adaptive equip/Assistive devices	39%	6%	26%
i. Residential support	37%	4%	24%
j. Physical therapy	36%	2%	24%

k. Rec./Leisure support services	33%	6%	39%
l. Occupational therapy	31%	5%	21%
m. Communication & lang service	27%	5%	36%
n. Employment services	27%	4%	25%
o. Respite care for caregivers	26%	8%	26%
p. Vision services/Support	23%	5%	26%
q. Vocational/Technical education	20%	1%	28%
r. Orientation & mobility services	19%	8%	20%
s. Mental health or counseling	15%	12%	16%
t. Food assistance/Stamps	15%	5%	19%
u. Sign language interpreting	14%	5%	17%
v. Self help/Support groups	10%	6%	30%
w. Adult literacy/Education	2%	8%	17%

Community Involvement

Deaf-blindness severely limits an individual's contact with people and things in the environment. This isolation often impedes his or her ability and opportunity to participate in community activities (Haring & Romer, 1995). Isolation, compounded with difficulties in communicating with others, puts individuals who are deaf-blind in jeopardy of not developing a social support network (Gee, 1994; Haring & Romer, 1996). The lack of a support network may further result in limited access to community activities.

In order to gain insight into the current involvement of youth who are deaf-blind in community/recreational activities, parents were asked to indicate which of 16 listed activities their child participated in routinely or at least twice a month. Most do not routinely engage in a wide variety of activities (Table 18). Their responses raise concern about the extent to which participation in community activities is limited for deaf-blind youth. Activities receiving fairly high response rates (50%-60%) included shopping/banking, going for a walk or to a park, going out to eat, and attending a religious service.

In response to the question, "Does your child have friends other than family members or paid people (service providers)?" nearly 50% of the youth were reported as having no friends other than family members or paid people. This fact, plus lack of participation in community activities, was one of the most dramatic results of this study. These young adults are isolated not only by the nature of their disabilities but also because they lack friends or a social life outside of the family.

Table 18. Community Involvement (Engaged at least 2 times per month) (N=97)

a. Shopping/Banking	60%
b. Going for a walk or to a park	60%
c. Going out to eat	57 %
d. Attending a religious service	41%
e. Visiting a friend	38%
f. Enjoys outdoor activities (e.g., hiking)	26%
g. Going to the movies, concert, or play	25%
h. Going to a meeting of a club or organization	20%
i. Going to the library	18%
j. Going to a sporting event	13%
k. Participating in Special Olympics	13%
l. Going on date or to a party	12%
m. Participating in individual sports	10%
n. Using the Internet/e-mail	7%
o. Participating in team sports	6%
p. Taking adult classes (fitness, art, etc.)	4%

These results regarding community involvement address issues that go far beyond programs, placements, and support services. In addition to having an individual job and home, access to the community for recreation and leisure is essential for all members of our society. Access to friends and activities can be the vehicle that allows "travel from loneliness and isolation to socialization and a richer life" (Bettica, 1976, p.7).

Living Arrangements

Housing opportunities for people with disabilities have changed from the traditional sheltered, segregated options toward a wide array of alternatives within the community (Racino, Walker, O'Connor, & Taylor, 1993). This study asked parents to report their child's current living arrangement (Table 19) as well as where they would like their children to live within the next several years. Currently, well over half of the youth live at home with their family.

Table 19. Living Arrangements (N=95)

At home with family		61%
Residential Care Environment		34%
Supportive living arrangement	15.8%	
Foster home	1.0%	
Nursing home	2.1%	
Residential college/Training program	2.1%	
Public institution	3.2%	
Private institution	5.3%	
Other	4.2%	
Living independently		5%

One of the most significant findings regarding living arrangements was that one-third of the parents would like their child to move to a supportive living arrangement within the next several years. The most disconcerting result was that over 10% of the youth are living in either public/private residential institutions or nursing homes.

Employment

Individuals with disabilities are often reported to have high rates of unemployment. This study found an unemployment rate of over 80% among this group of youth who are deaf-blind (Table 20). Only two of the youth were working full time and only three were competitively employed. Since the national unemployment rate at the time of the study was well under 5% for the general population, this extremely high rate of unemployment for these youth who are deaf-blind is problematic.

Table 20. Employment Statistics (N=94)

Unemployed	82%
Working for pay	18%
Working full-time	2 youth
Working part-time	13 youth

This dim picture of the employment status of youth who are deaf-blind may be explained by considering the reasons provided by the parents/caregivers for the youth's unemployment or underemployment (Table 21). Although no parent said they did not want their child to work, more than one third indicated that they did not think their child was capable of work (Table 21, a). If parents see their adult children as incapable, the young people will have little opportunity to demonstrate their capacity for work (Bryen, Newman, Reiter, & Hakim, 1987).

Table 21. Reasons for Unemployment or Underemployment (N=97)

a. I don't think my child is capable	34%
b. Lack of/underdeveloped job skills	27%
c. Lack of jobs in the area	25%
d. Lack of ongoing supports	20%
e. Lack of job training programs	18%
f. No one to help fund a job	12%
g. Lack of initiative/doesn't appear to want to work	11%
h. Not able to work because of health	10%
i. Waiting list for supported work	10%
j. No transportation available	9%
k. Don't want wages to impact on SSI benefits	7%
l. Waiting list for sheltered workshop	7%
m. I don't want him/her to work	0%

Over the past decade, there has been an increasing emphasis on providing services to support individuals with the most severe disabilities to participate in employment and other aspects of independent adult life (Johnson, Bloomberg, McGrew, Price, & Lin, 1992; Johnson, McGrew, Bloomberg, Lin, & Bruininks, 1995). There is growing evidence that all adults who are deaf-blind can work, provided the appropriate supports are in place (Everson, 1995). The results of this study in which parents report a lack of jobs (Table 21, b) and employment supports (Table 21, d), indicate that these youth require support to engage in employment. The exclusion of youth who are deaf-blind from the workforce appears to have less to do with type or severity of disability than with programmatic and personnel barriers in supported employment (Everson, Burwell, & Killam, 1995).

An additional notable result of this present study was that over one quarter of the parents reported that their children lacked or had underdeveloped job skills (Table 21, b). These results are compatible with the secondary school experiences of these youth. Their secondary school experiences did not reflect educational practices that are recognized to promote employment: community-based instruction, job sampling, cooperative education, and developing direct work related skills. Although it may not be the only factor that explains this extremely high rate of unemployment, there is every indication that appropriate application of transition-sensitive best practices in secondary education may be a major factor affecting post-school success.

includes the recognition that individuals who are deaf-blind need and have a right to communicate. No student should leave school without some formal and effective communication system. The provision of appropriate specialized services appears to be the key to ensuring that these individuals do not lead a life of isolation and nonproductivity. Second, those responsible for the provision of education and support to individuals who are deaf-blind need to develop ongoing protocols to assess the effectiveness of their efforts and ensure that these individuals are being provided with appropriate support and services. Parents and individuals themselves must be included in the development of services and the ongoing evaluation of effectiveness. One of the most striking results of the current study was that 80% of youths were not working for pay. It is clear that outcomes for youth who are deaf-blind must be dramatically improved. This can only be accomplished by monitoring the outcomes of youth and adjusting educational support as needed.

References Cited

Baldwin, V. (1991). Understanding the deaf-blind population census. *TRACES, 1*(2).

Baldwin, V. (1992, March). Population/demographics: Presentation. Perspectives on excellence. *Proceedings of the National Conference on Deaf-Blindness: Deaf-Blind services in the 90's* (pp. 53-72).

Baldwin, V. (1993, October). *Population/demographics.* Paper prepared for the National Project Directors' Meeting on Educational Services or Children and Youth with Deaf-Blindness, Washington, DC.

Best, T. (1992, March). Developing quality services: Perspectives on excellence. *Proceedings of the National Conference on Deaf-Blindness: Deaf-Blind services in the 90's* (pp. 29-41).

Bettica, L. J. (1976). Recreation for the deaf-blind: A rehabilitation approach. In J. Nesbitt (Ed.), *Professional recreation service and programs for deaf-blind* (p.17). Des Moines, IA: National Institute on Program Development and Training in Recreation for Deaf-Blind Children Project.

Blackorby, J., & Wagner, M. (1996). Longitudinal postschool outcomes of youth with disabilities: Findings from the National Longitudinal Transition Study. *Exceptional Children,* 62(6), 399-413.

Boys' Town National Research Hospital. (1990). *Heredity deafness newsletter of America.* Omaha, NE: Author.

Brown, L., Branston, M. B., Hamre-Nietupski, S., Pumpian, I., Certo, N., & Gruenewald, L. (1979). A strategy for developing chronological age appropriate and functional curricular content for severely handicapped adolescents and young adults. *The Journal of Special Education, 13*(1), 81-90.

Bryen, D., Newman, E., Reiter, S., & Hakim, S. (1987). *Barriers to employability of persons with handicaps: A bi-national study in the United States and Israel.* Philadelphia: Temple University Developmental Disabilities Center (university-affiliated program).

Campbell, P. H. (1995). Supporting the medical and physical needs of students in inclusive settings. In N. G. Haring & L. T. Romer (Eds.), *Welcoming students who are deaf-blind into typical classrooms: Facilitating school participation, learning and friendships* (pp. 277 - 305). Baltimore: Paul H. Brookes.

Carr, E. G., & Durand, V. M. (1985). Reducing behavior problems through functional communication training. *Journal of Applied Behavior Analysis, 118,* 111-126.

Chadsey-Rusch, J., & O'Reilly, M. (1992). Social integration in employment and postsecondary educational settings: Outcomes and process variables. In F. R. Rusch, L. DeStefano, J. Chadsey-Rusch, A. L. Phelps, & E. Szymanski (Eds.), *Transition from school to adult life* (pp. 245-263). Sycamore IL: Sycamore Publishing.

Choss, S., & Fernandez, P. (1980). Neurological damage and behavioral disorders in rubella children. In E. R. Stuckless (Ed.), Deafness and rubella: Infants in the 60's, adults in the 80s. *American Annals of the Deaf, 125,* 998-1001.

Cobb, B. R., & Neubert, D. A. (1992). Vocational education models. In F. R. Rusch, L. DeStefano, J. Chadsey-Rusch, L. A. Phelps, & E. Szymanski (Eds.), *Transition from school to adult life: Models, linkages and policy* (pp. 93-113). Sycamore, IL: Sycamore Publishing.

Collins, M. T. (1995, May-June). History of deaf-blind education. *Journal of Visual Impairment & Blindness,* 210-212.

Collins, M. (1993). Communication: Reaction. In J. W. Reiman & P. A. Johnson (Eds.), *Proceedings from the National Symposium on Children and Youth Who Are Deaf-Blind* (pp. 141-144). Monmouth, OR: Teaching Research.

Crimmins, D. B., Gothelf, C. R., Rowland, C., Stillman, R. D., Linam, A., & Williams, C. (1995). Basic concepts of communication. In K. M. Huebner, J. G. Prickett, T. R. Welch, & E. Joffee (Eds.), *Hand in hand: Essentials of communication and mobility for your students who are deaf-blind* (Vol. I) (pp. 159-184). New York: American Foundation for the Blind.

Durand, V. M. (1990). *Severe behavior problems: A functional communication training approach.* New York: Guilford.

Everson, J. M. (Ed). (1995). *Supporting young adults who are deaf-blind in their communities. A transition planning guide for service providers, families and friends.* Baltimore: Paul H. Brookes.

Everson, J. M., Burwell, J., & Killam, S. G. (1995). Working and contributing to one's community: Strategies for including young adults who are deaf-blind. In J. M. Everson (Ed.), *Supporting young adults who are deaf-blind in their communities. A transition planning guide for service providers, families and friends* (pp. 131-158). Baltimore: Paul H. Brookes.

Falvey, M. (1986). *Community-based curriculum: Instructional strategies for students with severe handicaps.* Baltimore: Paul H. Brookes.

Ford, J., & Fredericks, B. (1995). Using interpreter-tutors in school programs for students who are deaf-blind. *Journal of Visual Impairment & Blindness, 89*(3), 229-234.

Forest, M., & Pearpoint, J. (1990). *Everyone belongs: Building the vision with MAPs.* Toronto: Center for Integrated Education.

Fredericks, H. D., & Baldwin, V. L. (1987). Individuals with sensory impairments: Who are they? How are they educated? In L. Goetz, D. Guess, & K. Stremel-Campbell (Eds.), *Innovative program design for individuals with dual sensory impairment* (pp. 3-12). Baltimore: Paul H. Brookes.

Frey, W. D. (1988, March). *A study of special education services to deaf-blind students: Executive summary.* East Lansing, MI: Disability Research Systems.

Gee, K. (1994). The learner who is deaf-blind: Constructing context from depleted sources. In K. Gee, M. Alwell, N. Graham, & L. Goetz (Eds.), *Inclusive instructional design: Facilitating informed and active learning for individuals who are deaf-blind in inclusive schools* (pp. 11-31). San Francisco: San Francisco State University, Dept. of Special Education, California Research Institute.

Gee, K., Harrell, R., & Rosenburg, R. (1987). Teaching orientation and mobility skills within and across natural opportunities for travel: A model designed for learners with multiple severe disabilities. In L. Goetz, D. Guess, & K. Stremel-Campbell (Eds.), *Innovative program design for individuals with dual sensory impairments* (pp. 127-157). Baltimore: Paul H. Brookes.

Goetz, L. (1993). *Full inclusion programs for students who are deaf-blind* (Funded by U.S. Department of Education, Services for Children with Deaf-Blindness Program, Grant #H025D30013). San Francisco, CA: S.F. State University, Dept. of Special Education, California Research Institute.

Gothelf, C. R., & Brown, F. (1996). Self-determination for all individuals. In D. H. Lehr & F. Brown (Eds.), *People with disabilities who challenge the system* (pp. 335-353). Baltimore: Paul H. Brookes.

Gothelf, C. R., Rikhye, C. H., & Silberman, R. K. (1988). *Working with students who have dual sensory impairments and cognitive disabilities: A handbook for special education teachers and related services personnel.* Albany: New York State Education Department.

Halpern, A. (1993). Quality of life as a conceptual framework for evaluating transition outcomes. *Exceptional Children, 59*(6), 486-498.

Haring, K. A., & Lovett, D. L. (1990). A follow-up study of special education graduates. *The Journal of Special Education, 23*(4), 463-477.

Haring, N. G., & Romer, L. T. (1995). *Welcoming students who are deaf-blind into typical classrooms: Facilitating school participation, learning and friendships*. Baltimore: Paul H. Brookes.

Haring, N., & Romer, L. (1996). *Lifestyle planning and enhancement project* (Funded by U.S. Department of Education, Services for Children with Deaf-Blindness Program, Grant #H025D30001). Seattle: University of Washington, Dept. of Special Education.

Hasazi, S., Gordon, L., & Roe, C. (1985). Factors associated with the employment status of handicapped youth exiting high school from 1979 to 1983. *Exceptional Children, 51*, 455-469.

Huebner, K. M., Prickett, J. G., Welch, T. R., & Joffee, E. (Eds.). (1995). *Hand in hand: Essentials of communication and mobility for your students who are deaf-blind* (Vol. I). New York: American Foundation for the Blind.

Johnson, D. R., McGrew, K., Bloomberg, L., Lin, H. C., & Bruininks, R. H. (1995). *Descriptive findings of the national transition study of individuals with severe disabilities leaving school.* Minneapolis: University of Minnesota, Institute on Community Integration.

Johnson, D. R., Bloomberg, L., McGrew, K., Price, L., & Lin, H. (1992). *National outcome survey on the transition of individuals with severe disabilities.* Minneapolis: University of Minnesota, Institute on Community Integration.

Johnson, J. R., & Rusch, F. R. (1993). Secondary special education and transition services: Identification and recommendations for future research and demonstration. *Career Development for Exceptional Individuals, 16*, 1-18.

Mar, H. (1992). Psychosocial services: Presentation. In J. W. Reiman & P. A. Johnson (Eds.), *Proceedings from the National Symposium on Children and Youth who are Deaf-Blind* (pp. 97-111). Monmouth, OR: Teaching Research.

McDonnell, J., Ferguson, B., & Mathot-Buckner, C. (1992). Transition from school to work for students with severe disabilities: The Utah community employment placement project. In F. R. Rusch, L. DeStefano, J. Chadsey-Rusch, A. L. Phelps, & E. Szymanski (Eds.), *Transition from school to adult life* (pp. 33-49). Sycamore IL: Sycamore Publishing.

Mount, B. (1992). *Person-centered planning: Finding directions for change using personal futures planning*. New York: Graphic Futures.

Mount, B., & Zwernik, K. (1988). *It's never too early, it's never too late. A booklet about personal futures planning*. Minneapolis: Metropolitan Council.

Nisbet, J. (1992). *Natural supports in school, at work, and in the community for people with severe disabilities*. Baltimore: Paul H. Brookes.

Nisbet, J., & Hagner, D. (1987). Review of competitive employment: Issues and strategies. *Journal of the Association for Persons with Severe Handicaps, 12*, 76-79.

O'Brien, J. (1987). *A guide to lifestyle planning: A comprehensive guide to the activities catalog.* Baltimore: Paul H. Brooks.

O'Donnell, N. (1991). *A report on a survey of late emerging manifestations of congenital rubella syndrome.* New York: Helen Keller National Center.

O'Leary, E. (1992). *Infusing transition into the IEP: A synopsis of the final regulations.* Transition Update (Iowa Transition Initiative, Fall/Winter, 1992).

Perreault, S. (1993). Adult services: Reaction. In J. W. Reiman & P. A. Johnson (Eds.), *Proceedings from the National Symposium on Children and Youth who are Deaf-Blind* (pp. 213-221). Monmouth, OR: Teaching Research.

Petroff, J. G. (1999). *A national transition follow-up study of youth identified as deafblind: Parent perspectives.* Doctoral Dissertation, Temple University, Philadelphia.

Prickett, J. G. (1995). Manual and spoken communication. In K. M. Huebner, J. G. Prickett, T. R. Welch, & E. Joffee (Eds.), *Hand in hand: Essentials of communication and mobility for your students who are deaf-blind* (Vol. I) (pp. 261-286). New York: American Foundation for the Blind.

Racino, J. A., Walker, P., O'Connor, S., & Taylor, S. J. (Eds.). (1993). *Housing, support, and community: Choices and strategies for adults with disabilities.* Baltimore: Paul H. Brookes.

Reiman, J. W., & Johnson, P. A. (Eds.). (1992). *Proceedings from the National Symposium on Children and Youth who are Deaf-Blind.* Monmouth, OR: Teaching Research.

Riggio, M. (1992, March). A changing population of children and youth with deaf-blindness: A changing role of the deaf-blind specialist/teacher: Reaction paper. *Proceedings of the National Conference on Deaf-Blindness: Deaf-Blind services in the 90's* (pp. 20-28).

Riggio, M. (1993). Population/demographics: Reaction paper. In J. W. Reiman & P. A. Johnson (Eds.), *Proceedings from the National Symposium on Children and Youth who are Deaf-Blind* (pp. 53-66). Monmouth, OR: Teaching Research.

Romer, L. T., & Romer, M. A. (1995). Developing educational plans to support valued lifestyles. In N. G. Haring & L. T. Romer (Eds.), *Welcoming students who are deaf-blind into typical classrooms: Facilitating school participation, learning and friendships* (pp. 17-35). Baltimore: Paul H. Brookes.

Rowland, C. (1987). Perspectives on communication assessment. In M. Bullis (Ed.), *Communication development in young children with deaf-blindness: Literature review III* (pp. 1-22). Monmouth, OR: Teaching Research.

Rowland, C., Schweigert, P., & Stremel, K. (1992). *Observing and enhancing communication skills: For individuals with multisensory impairments.* Tucson, AZ: Communication Skill Builders.

Stainback, S. & Stainback, W. (Eds.). (1995). *Curriculum considerations in inclusive classrooms: Facilitating learning for all students.* Baltimore: Paul H. Brookes.

Stremel, K. (1991, October). Communicating with people who have multiple sensory impairments. *American Speech-Language-Hearing Association, 33,* 31-32.

Stremel, K., & Schutz, R. (1995). Functional communication in inclusive settings for students who are deaf-blind. In N. G. Haring & L. T. Romer (Eds.), *Welcoming students who are deaf-blind into typical classrooms: Facilitating school participation, learning and friendships* (pp. 197-229). Baltimore: Paul H. Brookes.

Strong, C., Clark, T., Barringer, D., Watkins, S., Walden, B., & Williams, S. (1993). *Using tactile signals and cues with children who are deaf-blind.* Logan, UT: HOPE.

Van Dijk, J. (1967). The non-verbal deaf-blind child and his world: His outgrowth toward the world of symbols. *Proceedings of the Jaarverslag Institiuut voor Doven in Sint Michielsgestel, Holland* (pp. 73-110).

Villa, R. A., & Thousand, J. S. (1992). Restructuring public school systems: Strategies for organizational change and progress. In R. A. Villa, T. S. Thousand, W. Stainback, & S. Stainback (Eds.), *Restructuring for caring and effective education: An administrative guide to creating heterogeneous schools* (pp. 109-137). Baltimore: Paul H. Brookes.

Wagner, M. (1993). *The National Longitudinal Transition Study of Special Education Students: A summary of findings.* Menlo Park, CA: SRI International.

Wagner, M., Newman, L., & Shaver, D. (1989). *The National Longitudinal Transition Study of Special Education Students: Report on procedures for the first wave of data collection* (1987). Menlo Park, CA: SRI International.

Watson, D., & Taft-Watson, M. (1993). *A model service delivery system for persons who are deaf-blind.* Little Rock: University of Arkansas Rehabilitation Research & Training Center for Persons who are Deaf or Hard of Hearing.

Wehman, P. (1981). Training for competitive employment. In P. Wehman, (Ed.), *Competitive employment: New horizons for severely disabled individuals* (pp. 45-75). Baltimore: Paul H. Brookes.

Wehman, P. (1985). Toward the employability of severely handicapped children and youth. In P. Wehman & J. Hill (Eds.), *Competitive employment for persons with mental retardation: From research to practice.* Richmond: Virginia Commonwealth University Rehabilitation Research and Training Center.

Wehman, P., & Hill, J. (1980). *Instructional programming for severely handicapped youth: A community integration approach.* Richmond: Virginia Commonwealth University School of Education.

Wehman, P., Kregel, J., & Barcus, J. M. (1985). From school to work: A vocational transition model for handicapped students. *Exceptional Children, 52,* 25-37.

Wehman, P., Moon, M. S., Everson, J. M., Wood, W., & Barcus, J. M. (1987). *Transition from school to work: New challenges for youth with severe disabilities*. Baltimore: Paul H. Brookes.

Wehman, P., Moon, M. S., & McCarthy, P. (1987). Transition from school to adulthood for youth with severe handicaps. *Focus on Exceptional Children, 18,* 1-12.

Welch, T R., & Huebner, K. M. (1995). The deaf-blind child and you. In K. M. Huebner, J. G. Prickett, T. R. Welch, & E. Joffee (Eds.), *Hand in hand: Essentials of communication and mobility for your students who are deaf-blind* (Vol. I) (pp. 3-24). New York: American Foundation of the Blind.

Wolf-Schein, E. G. (1989). A review of the size, characteristics, and needs of the deaf-blind population in North America. *The AACEHI Journal, 15*(3), 85-100.