Changing Systems for Transition: Students, Families, and Professionals Working Together

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Abstract: The Point of Transition Service Integration Project was initiated in 1997 in California as a three-year model demonstration grant funded by the Department of Education. The goal of the project was to improve the level of cooperation and collaboration among public schools, the State Department of Rehabilitation, and the State Department of Developmental Services related to efforts assisting students with severe disabilities who are transitioning from school to adult life. This paper presents an overview of that project with a focus on the research questions to which it gave rise. Finally, based on findings gleaned from observation and stakeholder interviews, implications are offered and recommendations are developed to inform and improve practice.

Despite increasing efforts and legislation to ensure equal opportunities to access the labor market (ADA, 1990), unemployment of individuals with disabilities remains high. Recent data indicate that approximately seventy percent of working age (18-64) persons with disabilities who desire to work are still searching for employment opportunities (President’s Committee, 1999; N.O.D./Harris, 2000). The statistics are equally disappointing for youth with disabilities. Blackorby and Wagner (1996) reported that for youth with disabilities out of high school for 3-5 years, only 17% of students with multiple disabilities and 37% of students with mental retardation were employed.

During the past decade a national effort, the School to Work Opportunities Act (STWOA, 1994), attempted to help high school students acquire the necessary skills to successfully enter the job market. Although STWOA was intended to serve all students, recent studies indicate that youth with disabilities were under represented in STWOA initiatives (Hershey, Hudis, Silverberg, & Haimson, 1997; Miller, Hazelkorn, & Lombard, 1997; Silverberg, 1997). Unger and Luecking (1998) suggested that one possible explanation for this under representation could be that special education has its own system for providing transition services. Thus, other school-to-work services may be seen as redundant.

Interagency Collaboration

Compounding the difficulty inherent to the transition process for this population of students is a lack of interagency cooperation and collaboration. Katsiyannis, de Fur, and Conderman (1998) stated “the fragmented system of services within high schools and adult services are contributing to the failure of special education to prepare youths for the future” (p. 1). The Individuals with Disabilities Education Act of 1990 (IDEA) is very specific about the requirement for interagency cooperation and collaboration. IDEA requires that, by age 16, the Individualized Transition Plan must include a statement that outlines the projected services the student will require to transition successfully to adult life, and a corresponding statement of interagency responsibilities or linkages. Further, the amendments specify: “if an adult partner agency [e.g., Department of Rehabilitation (DR)] does not fulfill the agreed upon services, the educational agency must reconvene the IEP team and develop alternative methods to meet the transition objectives” [IDEA, 602(a)(20)]. This requirement is aimed at preventing cross-
agency finger pointing and “buck-passing” that occurs when transition services are not provided and plans fail, leaving families and students unsure of who should be held accountable.

Studies have indicated that interagency collaboration is a primary factor leading to successful transition outcomes for students with significant disabilities (Benz, Johnson, Mikkelson, & Lindstrom, 1995; Eliot, Alberto, Arnold, Taber, & Bryar, 1996; Everson & McNulty, 1992; Gajar, Goodman, & McAffee, 1993; Gallivan-Fenlon, 1994; Wehman, 1996). Snauwaert (1992) proposed that interagency collaboration is essential, in that “interagency coordination and/or capacity building is the most viable approach to transition policy, coupled in some cases with a legal mandate” (p. 516). Large bureaucracies, such as the three involved in transition collaboration, are often viewed as ineffective, cumbersome, and slow to adapt to change. Mutual adjustment is an additional important inter-organizational concept that addresses some of the concerns in bureaucratic settings. Lindblom and Woodhouse (1993) described this concept: “The key to a potential bureaucratic intelligence of democracy lies in whether the division of labor is set up in such a way that bureaucrats have a need to adjust toward each other and toward other political participants” (p. 67). Gardner (1992) promoted the idea that effective collaboration and service integration can only be accomplished through shared decision making.

Leadership

Leadership also plays a vital role in these collaborative systems change efforts. Much can be accomplished if individuals are designated by their agencies to take a lead role in cross boundary efforts. Sarason and Lorentz (1998) indicate, however, that very few organizations allow for such a role in their organizational charts. Clearly a designated role for “boundary crossers” would be useful in coordinating the transition process for students with significant disabilities.

Interagency cooperation, collaboration, and boundary crossing efforts are essential components in providing quality services to students in transition. Yet, if these services are not consumer driven and based on person-centered planning, how successful can they be? Examples of person-centered planning approaches include Personal Futures Planning (Mount & Zwernik, 1988), MAPS (Vandercook, York, & Forest, 1989), Essential Life Style Planning (Smull & Harrison, 1991), Group Action Planning (Turnbull & Turnbull, 1992), Lifestyle Development Planning (Malette et. al., 1992), and PATH (Falvey, Forest, Pearpoint, & Rosenberg, 1994). Everson (1996) notes that in person-centered planning, people’s needs are either matched to existing services, existing services are adapted, or new services are created. Several studies have examined the impact of person-centered planning, or lack of person-centered planning, on student outcomes (Everson & Zhang, 2000; Lichtenstein & Michaelides, 1993; Malette et al.).

Point of Transition Service Integration Project

A number of federal demonstration projects have been funded to address these system deficits. One in particular, the Point of Transition Service Integration Project (POTSIP) (Certo, Pumpian, Fisher, Storey, & Smalley, 1997), initiated in the state of California, provided the context for this study. The project addressed the fragmentation of services among DR, Developmental Disability Services (DDS), and public school service delivery systems. The project goal was to effect a systems change by increasing the level of collaboration and cooperation among three agencies prior to the student’s “aging out” or exiting the public school system. Strategies such as early intervention, shared funding, and regular interagency committee meetings have been utilized, resulting in positive employment and other post-school outcomes for many. However, further research was warranted to find out if the use of these strategies made a difference to those involved. This study reports the responses of four students, their families, teachers, and adult agency personnel as they reflected on effects of the transition process. In other words, what was the impact on their quality of life?
Method

Case study methodology was selected for this study. The purpose was to inform practice related to transition planning for students with significant disabilities, guided by the following questions:

1. How do students with significant disabilities, their families, transition teachers, and adult agency staff perceive the transition process 12–24 months after exiting school?
2. Does interagency collaboration and early intervention impact the transition service delivery system from the perspectives of students, families, teachers, and adult agency representatives?

Participants

All four students/graduates were 23-25 years old and had participated in POTSIP. For purpose of this study, the term “student” has continued to be used although participants have technically exited from the public school system. Each of these students had been identified as having a severe disability, received some form of supported employment services, and had been categorized by the POTSIP model as having made a seamless transition from school to adult life. The research focused on stakeholder perceptions of the transition process 12-24 months after graduation. An attempt was made to select students who progressed along varied transition paths, either toward individual or group supported employment or toward a shared funding work/day program. This purposeful selection was used to ensure a cross-section of individuals; such a cross-section would provide maximum information. After students were selected, and appropriate consent forms were obtained, additional stakeholders were identified for interviews including the following for each student: the parent(s) and/or other significant family members, the primary transition teacher, and the adult agency representative involved with the student’s transition experience.

Data Collection

There were three data gathering techniques: observations, interviews, and review of documents. Students who were interviewed and observed in this study are considered to be in an “at risk” population. Special consideration was given to ensure that all participants were protected from harm, and a full review of human subjects was conducted and approved prior to gathering data.

Data Analysis

The lead author conducted all interviews, and reviewed all transcriptions of interviews. Data were analyzed for themes and categorized into broad areas with highlighted quotes and examples that supported each category. Transcripts were utilized to describe each individual case study and for a cross study analysis to explore common themes related to transition planning in general.

Limitations

Every effort was made to report data accurately and to triangulate data with project stakeholders, documentation, and member checks. Identifying four students constitutes a limited sample, but can provide the basis for a larger study where results may then be generalized to other students in similar settings. Individual differences unique to each student were anticipated, yet discoveries regarding stakeholder perceptions of service systems involved may inform practice and thus be useful for other parties attempting to improve interagency collaboration regarding school to adult life transition.

Findings

A case study summary was compiled for each student, based on information obtained through interviews with the student and family members, their transition teacher, and adult agency representative. Observation data were summarized to provide contextual information for each student. The original study detailed summaries of all stakeholder interviews, observation data, and record review. All information is not included in this article, but is available in Noyes (2002).

Table 1 highlights details discovered about each student. Information summarized includes: age at time of interview; disability la-
**TABLE 1**

Student Descriptions

<table>
<thead>
<tr>
<th>Student</th>
<th>Age</th>
<th>Disability Label(s)</th>
<th>Living Arrangement</th>
<th>Job at time of Transition</th>
<th>Non-work Activities at Time of Transition</th>
<th>Job at Time of Interview</th>
<th>Non-work Activities at Time of Interview</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sally</td>
<td>24</td>
<td>Mod/severe MR; history of self-abusive behaviors</td>
<td>Lives with parents</td>
<td>Shredding facility (15 hrs/wk; sub-minimum wage)</td>
<td>YMCA (exercise); adult ed. classes; mobility training on public transportation</td>
<td>Unemployed</td>
<td>Volunteer work at animal shelter &amp; thrift store; YMCA (exercise); ROP class (stamp-making)</td>
</tr>
<tr>
<td>Victor</td>
<td>24</td>
<td>Mod/severe MR; communication disorder</td>
<td>Lives with parents</td>
<td>Grocery clerk (30 hrs/wk; $6.75/hr)</td>
<td>Computer class; YMCA (exercise)</td>
<td>Grocery clerk (30 hrs/week; $7.55/hr)</td>
<td>Interested in pursuing more classes &amp; drivers license</td>
</tr>
<tr>
<td>Emily</td>
<td>24</td>
<td>Mod/severe MR; behavioral challenges</td>
<td>Board &amp; care facility</td>
<td>Not working</td>
<td>Volunteer as teacher aide; computer class; YMCA for exercise</td>
<td>Unemployed (had been employed at 3 jobs in prior 2 years)</td>
<td>Library; shopping; gym; helps care provider</td>
</tr>
<tr>
<td>Frank</td>
<td>3</td>
<td>Mod/severe MR; behavioral challenges</td>
<td>Lives with mother &amp; nephew</td>
<td>Bookstore (15/hr/wk; $6.25/hr)</td>
<td>Volunteer work at recycling center; Special Olympics</td>
<td>Discount store (6 hrs/wk; $6.75/hr)</td>
<td>Volunteer work at recycling center; Special Olympics; supported recreational activities</td>
</tr>
</tbody>
</table>
bels; living arrangements; vocational status at time of transition and interview; and non-work activities (e.g., recreation, continuing education, socialization) at the time of transition and interview.

Discussion

Individual case studies were examined for consistency and variance in stakeholder perspectives based on interview and observation data. In this section, each student’s story is described as related to stakeholder perspectives. Next, themes are examined in the context of the research questions and their impact on the service delivery system. Finally, recommendations are offered for practitioners and policy-makers and for future research.

Frank

Frank’s case study revealed the most consistency in terms of stakeholder perceptions. Frank, his mother, teacher, and job coach all felt his was a very smooth and seamless transition to adult life. No one reported any difficulties with transition planning or implementation, or in terms of interagency collaboration. The teacher indicated that he would have liked to see more paid hours developed for Frank, but after that occurred, Frank’s inappropriate stealing behavior was the major barrier to improving his paid employment opportunities.

Victor

Victor was the most dissatisfied with the outcome of his transition. Other stakeholders were aware of his unmet needs and admitted that policy barriers or lack of collaboration interfered with addressing his long-term goals. In this sense, the stakeholders were consistently unsatisfied with the non-work outcomes for Victor. Stakeholders, including Victor, were in agreement regarding employment and were satisfied with the job placement at time of graduation. Victor just wanted more. His dream of being able to drive and to access vocational training to do a job he really enjoyed was unfulfilled. Other stakeholders were all aware of this, but nothing happened. DR staff determined Victor’s case to be a success based on his employment, and closed his file without consideration of the training issue. The school system dropped out of the picture at graduation. Regional Center (Department of Developmental Disabilities) staff has not addressed the remaining goals, causing Victor to feel it to be a waste of time for him to attend further planning meetings. Unlike the other students who participated in the study Victor exhibited his level of frustration during the interview. His lack of faith in the adult systems, combined with his mother’s fear of confronting the adult agency, left them in an apparent state of helplessness in terms of addressing future goals. If they had not conducted the interview, the two observers at his work site would have judged Victor to be a young man working happily and successfully in an integrated environment. Working a 30-hour week and earning more than minimum wage typically indicates a successful employment outcome. Unfortunately, in Victor’s case this success did not result in an improved quality of life.

Sally

Sally, her teacher, and her job coach all seemed to view her transition as very successful; however, the family was not in total agreement. The parents acknowledged that Sally is probably very content in her current program, but they would like her to do more. Sally did not seem to have the same interest in working for money that her family did, but they would like to see Sally challenged to reach her full potential. The teacher, coach, and family were pleasantly surprised with how well Sally had adjusted to the community program and how her inappropriate behaviors eventually diminished. They all expressed initial doubts as to Sally’s ability to function successfully in the community. Sally would likely have gone to a sheltered workshop if there had not been the period of overlap between school and adult services.

Emily

Emily’s case presented an interesting incongruence of perspectives. Both Emily and her care-provider indicated that they were very
satisfied with the transition process and the outcomes. Their recollection was that the paid job had already been in place at the time of graduation, although it actually did not develop until September, two months following her exit from school. The teacher and the job coach indicated dissatisfaction with the transition outcomes. The teacher’s recollection was also that the job had already been arranged by graduation, but he was concerned that Emily’s community access needs had not been addressed sufficiently. The job coach was the most disappointed, and said that it made him sad in terms of not being able to focus on Emily’s long-term goals or to find assistance for her to attend child care classes successfully. The coach felt Emily could have “done much more” with proper support.

Themes Across Participants

The following themes emerged from the individual case-study review: an apparent “seamless transition” for Frank; “lack of agency follow through” or “dropping the ball” for Emily and Victor; “success is more than a job” for Victor; and “lack of communication” among stakeholders for Sally. In Victor’s case, adult agencies seemed to go their separate ways, with no one continuing the effort to meet his long-term objectives. For him, successful employment did not translate into a successful transition. Emily and her care-provider appeared to have lost sight of Emily’s “true goals” at this point, and no one seemed focused on anything else but finding a new job with better hours. Sally’s family’s perception of the transition process may have been different if there had been better communication among the stakeholders involved with her transition process, specifically helping them understand how services were actually overlapping that last year.

Positive Impact on Service Delivery

Gallivan-Fenlon (1994) utilized qualitative methods to gather data on eleven students in the process of transition from school to adult life in order to understand how the students, families, and service providers experienced and perceived the transition process. Semi-structured interviews, participant observations, and document examination were applied to conduct the study over a 16-month period, which included 10-months of the last year of school through 6-months after exit. It should be noted that the research was conducted prior to the implementation of IDEA. All eleven students had been labeled as having either moderate or severe disabilities and were projected to receive supported employment services following graduation. The author also attempted to assess the level of inter-agency collaboration that existed in the transition process and included parents, teachers, transition program coordinators, and service coordinators as participants. Disturbingly, data “revealed that transition, at least at the time of the study (1990) was not being experienced or managed the way policy makers, researchers, and authors proposed that it should be” (p. 20). The author’s statement represents a challenge to us to examine the evolution, if any, of perceptions regarding transition during the last ten years.

Themes across stakeholder groups in this study were examined in the context of the research questions. The following list groups the themes (noted in italics) and describes their positive impact on transition service delivery practices.

1. No sitting home, early planning, seamless transition, continuity of services and relationships, overlap of services, a whole year to work with them, introduce to adult programs in a slower, more coding manner. All of the students had a program of activities that they could continue to attend after they left school, that is, the first day with the adult program was no different from the last day of school. Planning began in the fall of the last year of school, and there was a nine-month overlap of services between public schools and the adult agency. All necessary funding was in place at the time of graduation to continue activities. Students were able to establish relationships with their job coaches and other group members during that time to maintain a continuity of services. Students and families developed a more realistic picture of the transition to adult life.

2. Shared funding. There were two instances among the case studies where both DR and the Regional Center were funding the students at the same time for different services, eliminating the “either/or” dilemma for
choosing programs. DR paid for the hours that a student received from supported employment services and Regional Center paid for support for non-work activities (i.e., community access, education, recreation) as long as the student was working at least 10-12 hours a week.

3. Early funding from DR. The decision by the local DR administrator to allow DR funding for supported employment for students during their final year of school allowed flexibility for agencies to provide more support for non-work activities during that time. It also enabled other school districts that did not have funding for sub-contracts to implement the model for students targeted for supported employment and allowed the model to continue beyond the period of the grant funding.

4. No inappropriate programs. At least one student who might have been placed in a sheltered workshop due to her behavior difficulties was able to succeed in a community-based program because of early intervention and overlapping services.

5. Excellent records and extensive support from the teacher. The overlap of services allowed the adult agencies to leverage information already gathered by school assessments as well as from the personal knowledge and relationship the teacher had with the student.

6. Improved interagency collaboration. Regular meetings occur every three months that involve transition teachers, adult agency personnel, Regional Center and DR administrators or supervisors in an effort to improve interagency cooperation and address systems barriers, such as those identified by the stakeholder groups.

7. Improved employment outcomes. Three of the four students were involved in paid employment at the time of graduation.

**Recommendations for Practice**

The second list is a summary of the emerging themes which indicate that the POTSIP model has more work to do, and includes recommendations for practitioners and policy-makers.

1. **Lack of long term planning, successful transition is more than a job, dropping the ball, lack of continuity, lack of collaboration, lack of family advocacy training, lack of perception of quality in daily activities.**

   Recommendations:
   a. Implement the use of an interagency, integrated personal future-planning document that addresses long-term goals and career planning, and delineates the responsibilities of the various agencies to implement the activities beyond graduation. The legally mandated ITP (Individualized Transition Plan) is an example of this type of document, but it appears to be no longer technically significant after the student exits school, leaving students and families to fend for themselves.
   b. Advocate that DR policy makers evaluate and amend, as needed, any policies that make part-time supported employment work and on-going vocational training toward longer term career goals incompatible goals by law or practice.
   c. Implement family advocacy training programs within school transition programs.

2. **Lack of communication, running out of time.**

   Recommendation:
   a. Improve the quality and frequency of communication between school, adult agency providers, and families to let them know exactly where they stand in the transition service overlap, especially regarding permanent job placement activities.

3. **Lack of community supports, lack of friends, lack of support at adult education centers or community colleges for persons with developmental disabilities.**

   Recommendations:
   a. Develop a funding mechanism through the DDS/Regional Center system to provide social coaching for students/consumers still living at home that have community access needs but are currently supported solely by DR under supported employment.
   b. Convene an interagency task force to examine the current level of supports available for students with developmental disabilities at adult education classes or community colleges and collaboratively develop a support network that will allow access to appropriate vocational training.

4. **Shared funding – 60 day limit.**

   Recommendation:
a. Continue to work with DR, Regional Center, and adult agency administrators to increase incentives for providing shared funding for consumers and remove the 60-day limit on full funding by the Regional Center when a job loss occurs and DR funding stops.

5. Portability of adaptive equipment.
Recommendation:
   a. Convene an interagency work group at the state level to develop a uniform policy regarding the transfer of adaptive equipment (e.g., assistive technology) purchased by the school for use by the student upon graduation.

6. Transportation barriers.
Recommendation:
   a. Convene an interagency work group to examine and amend any policies or procedures that create barriers for students or consumers in accessing programs due to city or regional boundary concerns.

7. Lack of program opportunities for persons with more significant needs, Same funding rate regardless of level of disability.
Recommendation:
   a. Convene an interagency task force to address rate setting at the state level in terms of establishing incentives for agencies to work with students/consumers with the most significant disabilities within the community based system. Consider “differential funding” based on severity of disability.

8. Lack of statewide practice of early transition services.
Recommendation:
   a. Convene a meeting of DR and DDS state level administrators to discuss statewide implementation of successful practices of the POTSIP model, including early funding by DR and shared funding practices. Implement statewide dissemination of lessons learned through the POTSIP model.

Future Research

Future research possibilities include national and/or statewide surveys of current transition practices (e.g., the use of social coaching, shared funding, early use of supported employment dollars from other state DR systems, any overlap of services). A follow-up study in 3-5 years, similar to this inquiry, on San Diego POTSIP may be helpful to re-examine identified areas of concerns regarding policy or procedures. Also, a follow-up study on the four students involved in this investigation in 3-5 years might provide valuable information regarding emerging long-term support needs and provide a more comprehensive review of the adult service continuum.

In addition, an action research project working with state policy makers to identify other systems barriers to successful transition practice might have a positive impact on future policy decisions for persons with significant disabilities.

Conclusion

This study revealed some “good news” and some “bad news.” On the positive side, the POTSIP model appears to be demonstrating a much higher level of interagency collaboration on a local level than is happening nationally, as reported in the literature review. Use of sub-contracts and the early intervention of supported employment dollars by the local Department of Rehabilitation represent a significant systems change. No student in this study was left “sitting at home” at the time of graduation as in the majority of cases in Gallivan-Fenlon’s (1994) study. Three of four students were working, all were connected to an adult agency nine-months prior to leaving school, and all continued with the same agency two years after graduation.

On the other hand, the study revealed there is still much work to do. There is more to a “seamless transition” than employment. Data indicated that in at least two cases, long-term goals were either ignored or systems barriers prevented them from being addressed appropriately. The literature review presented numerous examples of person-centered planning, personal future mapping, and many other textbook procedures intended to help students achieve their goals. There was no indication at the time that those methods were employed in these instances, which represents a disparity between espoused theory and practice. Lack of an interagency planning document that incorporates all of the stu-
References


