Paving Rough Roads: Transition to life beyond the classroom as experienced by students with disabilities and their families

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Abstract

This grounded theory study employed in-depth interviews with nine student/parent dyads from eastern Canada. Youth with disabilities, aged 16 to 21, contributed narratives describing high school transitions. Shared experience that transcends disability categories produced powerful results. Three categories emerged: (1) transition facilitators; (2) transition constraints; (3) strategies for meaningful transitions. Higher level analysis revealed further relationships: the connection between perceived lack of support and burn out; the importance of self-advocacy; and the sense of "paving rough roads" for the next generation. The core variable, contextual influences, resonates with the five systems presented in the bioecological model of human development. A model demonstrating the interactions among categories, contexts and ecological systems is presented. This framework provides encouragement and cautionary notes for those working toward a meaningful transition and a place to belong for youth with disabilities.

Transitions are those intersections in life where history and future converge. Marn and Koch (1999) presented eight central tasks to accomplish when moving from adolescence into life as young adults: separate from family of origin, construct support network beyond the family, refine social skills, take on greater responsibility for decision-making, learn to be responsive to
feedback, establish identity, assume a sexual role, and make vocational choices. In western democracies there is also a dramatic contextual transition from the educational system to life beyond the classroom. For some this transition is the doorway to autonomy and economic self-sufficiency; for others it marks the onset of social isolation and financial dependence. The presence of disability negatively impacts on the transition outcomes for youth. How can this difference be understood?

The purpose of this study was to explore the transition experiences of youth with disabilities and their parents as they prepared for life after high school. Voices of youth and their parents are gradually gaining recognition in the research literature, yet there is little representation of a Canadian perspective. Grounded theory methodology guided data collection and analysis, yielding a model depicting the contextual influences on the transition process. This model has significant implications for youth with disabilities, their families, health professionals and educators, policy makers and government departments. It is crucial that we move beyond a simplistic microsystem approach to one that critically reflects on the multiple dimensions of transition. Meaningful outcomes for students with disabilities can be achieved when transition teams are informed by careful examination of the facilitators and constraints at all contextual levels.

The transition outcomes of students with disabilities in North America have been the focus of many research endeavours. Surveys that capture a moment in time, longitudinal studies and qualitative research studies will be examined. Transition initiatives, laws and policies will be considered in order to situate this study within the larger body of knowledge.

The Participation and Activity Limitation Survey (PALS) conducted by Statistics Canada (2001) indicated that 3.9% of youth between 15 and 24 years of age experience functional limitations. According to PALS 49% of adolescents with disabilities completed high school compared to 58% of their non-disabled peers; 53% were employed compared to 72% of non-disabled peers. These statistics raise concerns about the post-school outcomes for all youth, particularly those with disabilities.

There are several transition initiatives underway in Canada. For example, the National Education Association of Disabled Students (NEADS; n.d.) responded to the demand for improved resources in Canadian high schools by creating a transition guide and an accessible website based on focus groups with students with disabilities. Although many provinces are grappling with transition issues, there is no evidence of a cohesive national agenda addressing
the needs of adolescents with disabilities (Lupart, 2000). The transition planning guide developed by the Nova Scotia Department of Education (NSDOE, 2005) purports to centralize collaboration, self advocacy and person-centred planning; however, there is little information available regarding how these processes are translated into practice.

The United States appears to be setting the pace for implementing and documenting evidence-based transition programs. The source of this difference may be found in the Individuals with Disabilities Education Act (IDEA) of 1990, reauthorized in 2004 (Individuals with Disabilities Education Improvement Act, 2004). This law mandates transition services be included in each student’s education plan by age 14. Historically, vocational and residential outcomes were central, but now quality of life and self-determination are also emphasized (Dolyniuk et al., 2002). King, Baldwin, Currie, and Evans (2005) present an excellent synthesis of approaches to transition planning with a focus on role engagement and the person-environment fit. The Transition Supports Model presented by Hughes (2001) also concentrates on the intersection of student abilities and supports available within target environments.

The acknowledgement that multiple factors contribute to successful transition reflects a greater awareness of issues faced by people with disabilities including: underemployment, poverty, social isolation, poor health, and long waiting lists for services (Chadsey-Rusch & Heal, 1995; Gallivan-Fenlon, 1994; McColl et al., 2004; Patterson & Laniere, 1999). Wells, Sandefur, and Hogan (2003) reported that transition planning is incomplete for many adolescents with disabilities. Limitations of the system, concerns regarding transition team dynamics and characteristics of individuals with disabilities and their families all affect transition outcomes of American students with disabilities (Halpern, 1993; Koskie & Freeze, 2000; Wittenburg, Golden, & Fishman, 2002).

If successful transition is measured by the standards of employment, viable social connections, community participation and independent living, then an enormous discrepancy exists between young people with disabilities and their non-disabled peers. Studies targeting this divide were reviewed for both content and methodology. Most research into transition experiences published to date used questionnaires and checklists, restricting responses to a priori categories (e.g., Bullis, Bull, Johnson, & Peters, 1995; New York State Department of Education, 1999). Other researchers chose to use structured interviews with adolescents, parents, or professionals involved in transition planning, limiting both the breadth and depth of data collected (e.g., Chadsey-Rusch & Heal, 1995; Kueneman & Freeze, 1997; Lovitt & Cushing, 1999).
The National Longitudinal Transition Study (NLTS), the most comprehensive quantitative study in this subject area, was conducted in the United States from 1987-1992 (Blackorby & Wagner, 1996). Structured telephone interviews with a representative sample of over 8,000 students and parents gathered information on post-school outcomes for young people with disabilities in the areas of education, employment, and living arrangements. In a recent review of this data it was noted that both the presence and type of disability had greater impact on the transition outcomes than race, ethnicity, family structure, or number of siblings (Wells et al., 2003).

NLTS advanced to a second phase of data collection involving a cohort of 7,000 adolescents ages 13-16 for a period of 10 years (Wagner, Cameto, & Newman, 2003). Preliminary results indicated that community participation increased among students with disabilities from 46% to 59%. There was also a significant increase in the number of students with disabilities who earned above minimum wage (from 41% to 68%). Employment was stable or increased among adolescents in most disability categories, with the notable exception of youth with emotional disturbance whose employment declined by 16%. Overall the results of the NLTS2 indicated that adolescents with disabilities are more involved in their communities through recreation, employment, and as consumers managing their own finances. Results imply that strategies mandated in IDEA are improving transition outcomes in the U.S. There are no similar longitudinal statistics available in Canada.

Qualitative studies gained momentum during the past decade, though quantitative research on youth transition published in peer reviewed journals continues to dominate the field. The comment made by Gallivan-Fenlon (1994) continues to be timely.

The importance of qualitative studies that examine experiences and perspectives of participants in the transition process cannot be overly emphasized. ...Unless we begin to understand the process of transition and how it is experienced and responded to by those who are living it, we will fail to implement it successfully. (p. 12)

Existing qualitative research explored the transition experience of stakeholders, particularly parents and professionals (e.g., Hanley-Maxwell, Whitney-Thomas, & Mayfield-Pogoloff, 1995). Studies that included student perceptions of the process targeted specific diagnostic groups, including cognitive impairments (Gallivan-Fenlon, 1994), learning disabilities (Lichenstein, 1993), autism (Nuehring & Sitlington, 2003), physical disabilities (King, Cathers, Polgar, MacKinnon, & Havens, 2000; Stewart, Law, Rosenbaum, & Willms, 56 Exceptionality Education Canada, 2007, Vol. 17, No. 1
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(2001), and multiple disabilities (Ferguson, Ferguson, & Jones, 1988; Zollers, 1992).

One study explored the experiences of youth with physical disabilities in Canada (Stewart et al., 2001). This study used focus groups and interviews to explore the transition experiences of a diverse sample of young adults ages 18-30 years old in the province of Ontario. That process revealed multiple pathways to transition, the lack of necessary skills many adolescents had for negotiating a way into the adult world, and emphasized the desire of young adults with disabilities to create individualized supports. Stewart and her colleagues acknowledged the importance of the synergy between the person and the environment during the transition process.

The purpose of this study was to understand and represent the transition experiences of students with disabilities in Nova Scotia. Two guiding questions emerged from the literature review. First, what are the lived experiences of the adolescents with disabilities and their parents during transition? Secondly, what is the shared experience of these young people that transcends disability categories?

Methodology

The framework of grounded theory produced a model describing the transition process of students with disabilities. This was accomplished by using constant comparative data analysis as defined by Glaser and Strauss (1967). The initial literature review revealed a dearth of research exploring the shared experiences of adolescents and their families across disability categories, thus meeting the criteria for grounded theory (Field & Morse, 1985). Research progressed through stages defined by Strauss and Corbin (1990). Data analysis in grounded theory involved reducing hundreds of transcribed interview pages into codes, then minor themes and major themes, until a core variable emerged.

The initial phase, open coding, consisted of assigning concise labels to participants' statements. For example, Emily commented, "I'm feeling... frustrated and aggressive. It's like I've been through too much. I can see I'm dying a slow death." The open codes "frustration" and "exhaustion" were assigned to this statement. After other interviews were completed, several open codes appeared to constitute a group (e.g., exhaustion, frustration, fatigue, weary, tired) creating a category labeled "burn out" in Table 1. Discovering connections between categories that combine into broader themes was the next step.
<table>
<thead>
<tr>
<th>Major Themes</th>
<th>Minor Themes</th>
<th>Category</th>
<th>Bioecological Level</th>
</tr>
</thead>
<tbody>
<tr>
<td>Transition Facilitators</td>
<td>Personal Facilitators</td>
<td>Personal control</td>
<td>Microsystem</td>
</tr>
<tr>
<td></td>
<td>Educational Facilitators</td>
<td>Responsive team</td>
<td>Mesosystem</td>
</tr>
<tr>
<td></td>
<td>Community Facilitators</td>
<td>Access to technology</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Inclusion</td>
<td></td>
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<tr>
<td></td>
<td>Governmental Facilitators</td>
<td>Acceptance by others</td>
<td>Exosystem</td>
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<tr>
<td></td>
<td></td>
<td>Accessibility</td>
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<tr>
<td></td>
<td></td>
<td>Accommodations made</td>
<td></td>
</tr>
<tr>
<td>Transition Constraints</td>
<td>Personal Constraints</td>
<td>Respite care</td>
<td>Macrosystem</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Funding</td>
<td></td>
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<tr>
<td></td>
<td>Educational Constraints</td>
<td>Burn out</td>
<td>Microsystem</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Negative perceptions</td>
<td></td>
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<td></td>
<td></td>
<td>Personal assistants</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>Lack of training</td>
<td>Mesosystem</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Inappropriate programs</td>
<td></td>
</tr>
<tr>
<td>Community Constraints</td>
<td>Governmental Constraints</td>
<td>Exosystem</td>
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<tr>
<td>Limited collaboration</td>
<td>Accessibility</td>
<td></td>
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<tr>
<td>Poor planning</td>
<td>Public transportation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Limited communication</td>
<td>Waiting lists</td>
<td>Macrosystem</td>
<td></td>
</tr>
<tr>
<td>Integration</td>
<td>Lack of programs</td>
<td></td>
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<td></td>
<td>Slow response</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>Lack of accountability</td>
<td></td>
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<tr>
<td></td>
<td>Poor access to information</td>
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</tr>
<tr>
<td></td>
<td>Technology costs</td>
<td></td>
<td></td>
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<tr>
<td>Participant Strategies</td>
<td>Parent Strategies</td>
<td>Microsystem</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Articulate goals</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Create partnerships</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Proactive planning</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Effective communication</td>
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</tr>
<tr>
<td>Student Strategies</td>
<td>Self-advocacy</td>
<td></td>
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</tr>
<tr>
<td></td>
<td>Persistence</td>
<td></td>
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</tr>
<tr>
<td></td>
<td>Articulate goals</td>
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</tbody>
</table>
this stage "burn out" was pooled with "negative perceptions of disability by others" and "difficulty with personal assistants" to create the minor theme "personal constraints." Table 1 indicates that four levels of constraints (i.e., personal, educational, community, governmental) generated the major theme "transition constraints."

The systematic process of grounded theory data analysis gradually exposed the core variable: contextual influence. This variable met the requirements presented by Strauss (1987): it repeatedly presented in the data, linked themes, explained data variation, and influenced theory development. The researcher worked within these analytical layers to create a model that incorporates the processes and themes that emerged. More detailed information regarding data generation and analysis will be presented after the participants are introduced.

Participants

The proposal for this research study was approved by the Human Subjects Review Board at Temple University. Purposeful and theoretical sampling were used to select participants from an Atlantic Canadian province who could offer unique perspectives as the research evolved (Cutcliffe, 2000). Personal contacts, professional networks, technology resource centers, and participant referrals were used to recruit five rural families and four urban families. Participants consisted of seven dyads (student and one parent) and two triads (student and two parents). The sample included nine students (two female and seven male) from 16 to 21 years old, nine mothers and two fathers, for a total of 20 participants in nine interviews. Three students came from single parent homes; six resided with both parents. Four students used wheelchairs for community mobility. Eight families were Caucasian and one family was Lebanese. No specific data were collected regarding family income; however, based on information volunteered during the interviews (e.g., parent employment status, type of employment) socio-economic status spanned all levels (two low income, five middle income, two high income). All parents signed statements of informed consent. Three participants signed a statement of informed consent. The remaining six students assented to participation, with parent/guardian signing proxy consent. The confidentiality of all participants was assured throughout all phases of research and dissemination. Table 2 presents participant pseudonyms and characteristics; however, detailed demographic information was excluded to protect participants.
### Table 2
*Participant Demographics*

<table>
<thead>
<tr>
<th>Name (parent/student)</th>
<th>Age</th>
<th>Stage of transition</th>
<th>Education background</th>
<th>Current housing</th>
<th>Housing aspirations</th>
<th>Vocational aspirations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Laura / Jody</td>
<td>16</td>
<td>Grade 10</td>
<td>Learning centre</td>
<td>Home</td>
<td>Shared apartment</td>
<td>Unclear</td>
</tr>
<tr>
<td>Joan / Chris</td>
<td>18</td>
<td>Grade 12</td>
<td>Learning centre</td>
<td>Home</td>
<td>Small Options</td>
<td>Supported employment; recreational focus</td>
</tr>
<tr>
<td>Will &amp; Kara / Pat</td>
<td>19</td>
<td>1st year university</td>
<td>Full inclusion</td>
<td>Home</td>
<td>University residence</td>
<td>Competitive employment</td>
</tr>
<tr>
<td>Emily / Kyle</td>
<td>20</td>
<td>Grade 12</td>
<td>Learning centre</td>
<td>Home</td>
<td>Home</td>
<td>Recreational focus</td>
</tr>
<tr>
<td>Luke &amp; Ally / Jamie</td>
<td>17</td>
<td>Grade 11</td>
<td>Full inclusion</td>
<td>Home</td>
<td>Own apartment</td>
<td>Competitive employment</td>
</tr>
<tr>
<td>Amanda / Logan</td>
<td>16</td>
<td>Grade 10</td>
<td>Learning centre</td>
<td>Home</td>
<td>Shared apartment</td>
<td>Unclear</td>
</tr>
<tr>
<td>Ruth / Mackenzie</td>
<td>20</td>
<td>2nd year university</td>
<td>Full inclusion</td>
<td>University residence</td>
<td>Own apartment</td>
<td>Competitive employment</td>
</tr>
<tr>
<td>Maria / Taylor</td>
<td>20</td>
<td>Community based</td>
<td>Learning centre then community based</td>
<td>Own apartment</td>
<td>Own apartment</td>
<td>Supported employment; recreational focus</td>
</tr>
<tr>
<td>Tori / Kelsey</td>
<td>20</td>
<td>Grade 12</td>
<td>Full inclusion then community based</td>
<td>Home</td>
<td>Small Options</td>
<td>Supported employment; recreational focus</td>
</tr>
</tbody>
</table>
Data Generation and Analysis

Each family engaged in one audiotaped interview lasting one to two hours. After completing all transcriptions, the researcher verified the accuracy of these documents by listening to audiotapes while reading transcripts. During the first four interviews the initial probe was broad: “Tell me about your experiences planning for life after high school.” As themes began to emerge through data analysis, the researcher created a guided interview format to ensure that upcoming participants could support or refute these tentative themes (Field & Morse, 1985; Noerger Stern, 1980).

The systematic nature of grounded theory demands that the researcher begin coding and analyzing data after the first interview. ‘In vivo’ codes were identified during analysis of the first interview (Field & Morse, 1985). Constant comparative analysis of each additional interview allowed the researcher to continuously challenge or enrich the emerging themes as new interviews were completed (Hutchinson, 1999). No unique information materialized in the last two interviews, nor were any aspects of the work found to be incomplete; therefore, theoretical saturation was attained by the ninth interview (Glaser & Strauss, 1967).

Multiple strategies were employed to ensure trustworthiness (Lincoln & Guba, 1985). Investigator subjectivity was acknowledged by recording data analysis procedures and presenting them to a judge panel comprised of the two professors supervising this study; one with expertise in the content area and the other in qualitative methodology. Member checks to confirm theoretical hunches were accomplished by mailing interview summaries to participants (Lincoln & Guba, 1985). Eight families returned the summaries and commented that the information was representative of their experiences. An occupational therapy professor completed an independent analysis of three transcripts. The codes and categories that emerged were congruent with that of the principal researcher, thus strengthening credibility.

Triangulation was achieved through the use of three separate strategies: interview, observation, and document review. Following the initial interview with four students who used alternative communication strategies, the researcher completed observational sessions in natural settings (e.g., home, community, educational setting). The researcher recorded fieldnotes describing communication strategies used by nonverbal students, responses of other people in the setting to the student, and the quality of student support observed. These observational sessions confirmed information gathered during interviews (e.g., the existence of architectural barriers; non-inclusive settings).
Copies of individualized education plans and other correspondence from government departments also substantiated interview data.

Dependability of results was determined by the transparency of the audit trail (Lincoln & Guba, 1985). Decisions made during the course of this study were recorded using the guidelines offered by Rodgers and Cowles (1993): personal response documentation, contextual documentation, methodological documentation, and analytical documentation. The principal researcher kept a journal to explore personal beliefs about relevant issues (e.g., disability, inclusion, family dynamics). It also situated the researcher in this project, giving consideration to the implications of being a white woman from Atlantic Canada with eight years of community-based experience as a pediatric occupational therapist.

The second form of journaling, contextual documentation, recorded environmental and relational observations made during interviews, media reports about disability issues, and lobbying efforts for policies affecting students with disabilities. The researcher included details of the interview setting in this journal. Methodological documentation focussed the rationale for decisions that influenced the direction of the study. This journal recorded the logic behind recruitment of participants and the development of interview questions. The final strategy was analytical documentation. Four levels of data analysis presented in Field and Morse (1985) were used: (a) category development and saturation, (b) formulating abstract definitions of each category, (c) exploitation of categories, and (d) establishing links between categories. These categories and connections are presented in the results section.

Limitations of Study

The researcher was the data collection instrument. Although this is sometimes viewed as source of bias or subjectivity, Glaser and Strauss (1967) argue that the systematic approach of grounded theory addresses this perceived limitation. The small number of interviews completed may have precluded saturation of all categories. More nuanced information may have been gathered if several interviews were conducted over time with each participant. Different perspectives may have emerged had parents and students been interviewed separately. The intent of the research was to include the voices of students and parents; however, because six students had language impairments, the research is more reflective of parent experiences. Although opportunities were presented for participants to provide feedback regarding data analysis, the researcher did not consider the power relations inherent in this dynamic. In future research alternative forums of feedback would be arranged.
Results

Data analysis, presented in Table 1, yielded three major themes: transition facilitators, transition constraints, and participant strategies. Both facilitators and constraints filtered into the same minor themes: personal, educational, community, governmental. All major and minor themes, substantiated by quotes from participants, are presented below.

Transition Facilitators: "He knew exactly who to call"

Personal supports were unique to each participant, surfacing in four interviews. Regardless of the type of support, these students were en route to self-advocacy and autonomy. When this group of students was compared to the remaining five students, the researcher noted that one factor appeared to differentiate these groups—the ability to communicate effectively. The students with strong communication skills described more frequent engagement with friends both in the classroom and in the community.

The educational system was the second minor theme identified. A powerful support within the educational system was the presence of a key person who could respond to student and parent concerns. The identity of this person varied among participants, but the critical role played was constant. Another valuable enabler was the provision of appropriate technology. Pat, a student attending university, reported, "I had a sip and puff computer... But now I have a voice activated system... So I can do anything with the computer." Technology made both the environment and relationships more accessible. The presence of well-trained and supportive personnel promoted inclusive education. Seven students had educational assistants during at least part of their school years. Consistent support staff enabled the student to engage effectively with teachers and peers in the classroom.

Although the researcher asked no questions about inclusion in the first five interviews the topic inevitably arose; hence, it became a topic on the interview guide. Inclusion was perplexing to the researcher, since it was identified as both a facilitator and a constraint to transition. Many participants commented on the value of inclusive education, while moments later discussed the negative aspects of this same policy. Although integration and inclusion were used interchangeably by participants, untangling these words resolved this discrepancy. Integration was interpreted as being educated parallel to peers but not with them, whereas, inclusion was viewed as an opportunity for the students to be engaged within accessible environments that valued diversity.
Finding a place to belong within a respectful community was identified as a major transition outcome by all families involved in this study.

Community supports was the third minor theme. Laura reported, “Jody has more of a social life than I do! We’ll go out and he’ll be greeting all these people.” Four students involved in the study used wheelchairs for mobility. Accessibility was identified as a major concern for these individuals, although Mackenzie noted that more venues were incorporating universal design. “[My university] is big on accessibility. If it’s not accessible, they’ll change it... Other places, like the community, is a lot different, but it’s getting better. I’ve seen a big change in the [past] five years.” Tori started a summer recreation program for children with disabilities in her small community 18 years before the interview. As the children grew older, it evolved into a vocational training program with tremendous community support.

Government was identified as the final facilitator. Three families recognized the respite care program as a valuable resource. Funding was a central theme in every interview. Six families received funding from one or more of three government departments: community services, education, and health. In each case funding was acquired, but only after a bitter struggle. One of the most poignant stories came from a parent whose child had behavioural concerns.

She went for 6 weeks without sleeping... we were both probably at the brink of death. It was really awful. I was psychologically very fragile. I took her to [a government office] with the encouragement of some friends... Taking a huge risk, I said, ‘I can’t keep her. She’s yours.’ I didn’t want that to happen... but that’s what got the ball rolling fast. There wasn’t a foster home in the county that would take her... The phones were just buzzing with panic because here’s this kid in the office with nowhere to go. Nobody wanted her, which was hard for me too, because here I’ve got this kid that nobody wants. But if nobody else wants her, then at least recognize that it’s more than I can cope with without your help. So I got services. I’ve got wonderful services... a full time educational assistant. She’s funded. Everything’s paid for.

Although the funding was critical to the student’s transition, the process for securing it was onerous. Further constraints to transition will now be presented.
Transition Constraints: “All dressed up and nowhere to go”

Participants reported constraints four times more often than facilitators. Four minor categories were identified: (a) personal, (b) educational, (c) community, and (d) governmental. Personal and educational constraints appeared with the same frequency in the data, with burn-out being the most common. This issue was raised by six parents, and by all those with children who had multiple disabilities, autism, or communication impairments. The three families with whom the issue of burn-out did not arise included: a student who became disabled in high school, a student whose parents had not yet chosen to address transition issues, and a student whose transition to university, though challenging, had been successful. No students identified personal burn-out. Emily reflected on burn-out noting, “I became very, very sick... That’s when it hit my mind that I needed help now. I [could not] do it alone. As he’s getting older, he’s getting heavier. It’s getting harder. My energy is running out.”

Burn-out was associated with the ongoing struggles parents faced within the educational system. “I’m pretty quiet on the school front only because I can’t deal with it anymore. I’d rather cut off my right arm than go through that school thing again.” It appears that the demands of caregiving, lack of personal supports, and the frequent conflicts with the government systems all contribute to the experience of burn-out.

Negative experiences with professionals created incredible stress for the parents in this study. “It’s been hard [for] me with teachers. I’ve learned that if I go in and meet a teacher and if I know more than them, then we’re in trouble.” Will experienced frustration due to the limitations professionals placed on Pat. “There’s always been a stigma attached that if you were physically disabled you were mentally disabled. They’re having a hard time separating the two... that you can be physically disabled but very bright.” Students who required the services of personal or educational assistants were faced with unique challenges. There were funding issues; however, identifying and building rapport with a service provider were equally problematic. Mackenzie commented,

A big barrier actually was just finding people to stay with me. It’s hard to have someone you don’t know come in and... trust to live with you. There’s agencies [out] there, [but] the money they’re looking for is so much. The government only gives you so much to work with.

Educational constraints presented significant challenges. Lack of professional training was raised by five families. Approximately half of the participants felt that school administration and staff did not collaborate with them.
The analogy of a battle being waged was used by most participants; however, Will used a different metaphor. "I felt from the beginning we were paving a rough and rocky road—all through the school system." Six families reflected on the repercussions of poor planning by the school districts. Maria explained,

They wanted her out of school fast. The last day she actually went full time to school, they called me to pick her up. I went in there. They had her in a dark room on a couch with four adults sitting on top of her. She was just wild. She was screaming in panic... They were all out of control... Nobody was prepared to cope with her behaviour. I just went over and took her by the hand and walked out of the school... It wasn't difficult for me to come to the realization that I didn't want her there.

Issues around inclusive education surfaced in each interview. Jody was involved in many social functions outside of school. His mother stated, "He gets enough integration. But as far as the academic part of it, it's based on his individual needs. If he is integrated, then that doesn't happen. The teacher doesn't have time." Other parents fought attitudinal barriers in order to have their children educated in the least restrictive environment and experienced integration when inclusion was the expectation.

The community barriers most commonly reported were related to physical accessibility and to public transportation. All those using wheelchairs reported significant physical barriers that impacted on transition experiences. Creating accessible schools did not appear to be a priority for the districts. "It took four and a half years to get the elevator at the school." Inaccessible public buildings were also problematic as was the lack of accessible bus transit routes. Those individuals who had access to public transportation met with scheduling challenges. "You have to call up three or four days in advance, sometimes even a week. [It's hard] if you have somewhere to go on the spur of the moment."

Government barriers were the most commonly reported obstacles to effective transition planning. Bureaucratic issues were encountered by many families in the quest for funding.

Someone from Social Services said, "Because there is no money you are put on a waiting list. You are number seven on the waiting list, but because of the amount of money you need, you quite possibly are farther down the list. And really the only way anybody moves up the list is if somebody from the top of the list doesn't need the funding anymore or passes away."
Even when funding was secured, families felt vulnerable to policy changes and budget cuts.

Lack of appropriate programs post-graduation was raised by the parents of four students with significant disabilities. Emily stated, "[Kyle] doesn't belong [in sheltered employment]... I would rather keep him home because... he is going to be forgotten in a corner." The perception of broken promises culminated in a generalized mistrust of government systems.

Five families commented on the slowness of government responses to inquiries. Tori spent years establishing a viable work training program for Kelsey. She noted, "We knew that there were enough individuals over this way that we could have something for our kids when they finished school. That was really our goal. You'd think that ten years would be plenty of time to do that. Not so." Poor access to information regarding funding, training programs, and supports concerned many students and parents. "It's absolutely amazing. Not one department knows what any other department is doing... and if they do know, they're not willing to tell you."

The expense of technology was astronomical for several participants; yet, its benefits were priceless. "Without the [power] chair someone would have to push me around. It's basically the biggest independence that I have — to move around when I want to." In order to best meet Kyle's physical needs, his family paid for extensive home renovations and specialized equipment. In addition to these one-time expenses, parents underscored the importance of considering ongoing expenses for students with medical needs. Monthly funding provided by the government did not meet these recurring costs.

**Strategies: "I'm going to put my feet down and knock on the door"**

Analysis yielded eighteen separate strategies used by parents to facilitate the transition process. Those used most often were: clearly articulating goals, creating partnerships, communicating effectively, and planning ahead. Either parents or the students themselves were able to discuss plans for the future. Two hoped to attain advanced university degrees. Two others wanted to share an apartment after high school. Joan explained the primary goal for Chris,

I would like to see her in a place where she is happy and safe... that she has something to do with her day that's meaningful... that she's living in a home that is her home, not some place where somebody is going to kick her out because of a lack of funding. I'd like to know that there is going to be some stability in her life.
Identifying people who were able to share the family’s vision for the future was pivotal. These “partners” were other parents, members of the community, government agencies, or advocacy groups. One family found it helpful to connect with someone who had recently experienced the process. The importance of effective communication was reported in six families. It was with the voice of experience that Tori reported, “One thing I know about when you’re working [with the] government and asking them for money, you can’t have other people do it for you. You have to speak out loud and clear for yourself.”

Proactive planning was also identified as a key to meaningful transition. Anxiety about the future was a significant catalyst for parents. Joan stated, “For one thing you have two aging parents. And then you might run into a situation where you have a crisis on your hands. One or both of us could end up in the hospital. What’s going to happen to her? A crisis situation doesn’t give you any time to plan.” Parents wanted assurance that their wishes for their nonverbal children would be honored.

Two students were experienced self-advocates. After acquiring his disability in high school, Mackenzie met with great resistance from the school administration upon his planned re-entry to the school system. In a meeting attended by representatives from governmental and educational departments, Mackenzie advocated on his own behalf. His message was simple, “I just told them right out that all I wanted was an education, and I felt I was just as eligible for one as anybody else . . . Why should I be deprived of an education because of my disability?”

Persistence was a strategy employed by two students. “You call someone . . . If they don’t get back to you by the time they say then you have to call them back. Persistence helps because they pass the buck.” Three other students demonstrated potential for becoming effective self-advocates given their ability to describe personal goals for work, housing and recreation. Logan explained to his parents and teachers that the demands of integrated education were too stressful. “I decided there [were] too many books and I [was] getting behind. So I needed a new start. And [I needed to] meet some new friends.” The remaining four students were nonverbal, using gestures, behaviours and eye gaze to communicate. These strategies all relied upon the ability of the communication partner to interpret the students’ messages. These students are believed to be the most vulnerable of all the participants. Tori summed up the issue of self-advocacy: “If you’ve got a client that’s pretty capable and can speak for themselves, they’re the ones that are O.K.”
All three major themes and their supporting minor themes and categories were reviewed in this section. It was at this stage of a grounded theory study that the researcher returned to the literature to discover connections between the results and extant research and theories (Creswell, 1998). These intersections are presented within a conceptual model that is grounded in the lived experiences of participants.

Discussion

During an intensive literature review it was noted that the minor themes described in this study—(a) personal, (b) educational, (c) community, and (d) governmental influences—resonated with four contextual levels presented by Bronfenbrenner (1979) in his seminal work on the bioecological model of human development: (a) microsystem, (b) mesosystem, (c) exosystem and (d) macrosystem. Of particular interest to the transition experiences of students with disabilities is the chronosystem, present in more recent incarnations of Bronfenbrenner’s model (1988/2005; 1992/2005). This discussion will accomplish four objectives. First, the five contextual systems outlined in the bioecological model will be defined. We then weave the findings of this study into Bronfenbrenner’s conceptual framework, creating a model describing the transition experiences of youth with disabilities and their families. Third, connections to Nova Scotia’s transition planning process will be established at each contextual level. Finally, recommendations made by participants for moving toward meaningful transition flow through the five contextual levels. These comments are included to explore the flexibility of the contextual model and to encourage critical thinking about the transition process.

Contextual Model of Transition Involving Youth with Disabilities

The bioecological model seeks to understand, explain and predict development over the life course. The influence and convergence of personal characteristics, situational elements, and developmental processes are central features. Efforts to embed the results of this study into the conceptual framework of the bioecological model of human development produced the schematic presented in Figure 1. The outermost arrows moving clockwise around the model represent the chronosystem. Bronfenbrenner (1988/2005) acknowledged that development can only be understood as a function of time. The chronosystem portrays life experiences and development in a cyclical relationship, with each shaping the other throughout the life course.
Both a person's age and the historical milieu of her generation are embedded in the chronosystem. The past 30 years brought about significant changes in disability policy. Section 15 (1) of the Canadian Charter of Rights and Freedoms (1982) states that "Every individual is equal before and under the law and has the right to the equal protection and equal benefit of the law without discrimination and, in particular, without discrimination based on race, national or ethnic origin, color, religion, sex, age or mental or physical disability." This law echoes the gradual shift in society's response to disability. It protects the rights of students with disabilities as they pursue educational goals, vocational opportunities and engage in community activities.

Nova Scotia recommends that transition planning begin no later than age fourteen (NSDOE, 2005); however, this did not occur for any research participants. The students involved in this study were at various stages in the transition process, with two recently completing their transition to university. The historical placement of this generation is critical. Physical and attitudinal
barriers are beginning to erode as the rights of citizens with disabilities are acknowledged, universal design is being incorporated into the built environment, and more flexible workplaces are emerging. Unfortunately, the societal inroads made by the Independent Living Movement in North America were not realized at the individual level for many students in this study.

While reflecting on the chronosystem it is important to note that the transition planning document produced by the Department of Education in Nova Scotia (2005) was released after the interviews for “Paving rough roads” were completed. At present a review of the special education system in Nova Scotia is underway. It will be important to attend to the findings of this panel, particularly regarding their assessment of the transition planning process outlined in 2005.

The four contextual levels, depicted as a ring in Figure 1, suggest multiple layers of influence affecting the individual’s transition experience. Although these four levels are described as separate entities, they are envisioned as fluid points along the continuum of context from microsystem to macrosystem. Each contextual level presents unique facilitators and constraints to the students’ transition. The participants countered the constraints with multiple strategies to promote positive transition outcomes. These forces are represented by the arrows linking each system to the student and parent, featured centrally in Figure 1. The facilitators available at each contextual level combined with parent/student strategies to promote meaningful transition outcomes. Results indicated that if positive influences were dominant, then the road was “paved” to meaningful transition. Constraints exerted from all systems had a negative effect on transition outcomes. If transition constraints prevailed, the road remained “rough and rocky” compromising transition outcomes. Recalling that constraints were referenced four times as often as facilitators during interviews, student and family strategies must achieve great potency to create positive momentum.

“Meaningful transition” identified in Figure 1 refers to the unique vision of the student with a disability and his or her family. It is recognized that personal traits, goals, resources, beliefs, culture and contextual influences intersect to construct an individual definition of success in the transition to life beyond high school. The model respects this diversity.
Microsystem: Personal Facilitators and Constraints

The microsystem is equated with the minor themes of personal facilitators and constraints from this study. It includes all immediate factors that contribute to or constrain individual development (e.g., roles, activities, physical impairments), highlighting the reciprocal nature of relationships. For example, the student is not only influenced by, but also exerts influence on her parents. A sampling of microsystems crucial to the transition process includes students embedded in their families, in the classroom environment and in job training sites. The impact of each higher order system is experienced in the microsystem; therefore, it is not surprising that most parents described burn-out from constant struggle with schools (meso), communities (exo) and government agencies (macro).

A fundamental dynamic surfaced between limited facilitators and the experience of burn-out in the parents. The families who did not mention the presence of consistent personal supports expressed feelings of burn-out most emphatically. Strong support from friends, extended family, and the community appeared to buffer parents. Given that families perceived system-wide hostility as the primary cause of burn-out, it is critical that the source of these barriers be identified and addressed. Respecting the contribution of family caregivers is critical to maintaining this valuable human resource.

Nova Scotia’s transition planning guide (NSDOE, 2005) appears to apply a person-centred approach that begins with the identification of students’ strengths and needs in terms of specified transition outcomes (e.g., employment, recreation, housing, transportation). This well-intended individualistic focus on independence can become problematic, given that the evaluation of strengths and needs does not extend to other people or systems. Were we to adopt an interdependent model for transition planning (Kim & Turnbull, 2004), it would become possible to identify the potential contributions and supports of all stakeholders and systems connected to students’ transition outcomes. Although enacted in the microsystem, conceptualizing transition planning as an interdependent process has implications throughout all contextual levels.

Mesosystem: Educational Facilitators and Constraints

The mesosystem is a set of interconnected microsystems that effect development. Educational facilitators and constraints parallel this system. This is exemplified in the convergence between home and school at an individual education planning session. Both settings (home and school) include the student and exercise influence on each other. The transition planning guide...
gestures toward this dynamic relationship highlighting the need for collaboration between home, school and community (NSDOE, 2005). Several school boards within the province have recently hired staff to support the transition process—an indicator that more resources are being allocated to training transition teams. There is some concern about the implications of particular phrases in the guide. For example, the document title, “Transition planning for students with special needs,” seems to indicate that transition planning is done on behalf of students, rather than with students and families. The term ‘special’ implies that only particular students have needs regarding transition planning. The strategies of self-advocacy, collaboration and the pursuit of student/family identified goals exist in tension with the title of the document. Perhaps this conflicted language gestures toward a systemic transition that will eventually result in more meaningful transition outcomes.

Power dynamics were evident at this level, with repercussions (i.e., burn-out) in the microsystem. Parents described unrelenting demands for vigilance due to a shortage of teachers with appropriate training and limited collaboration between classroom and home. Longstanding disempowerment of students and parents heightened the risk of burn-out, potentially compromising transition outcomes. Interdependence offers a supportable route forward, where schools, students and families recognize that they each need the knowledge and support of the others to achieve meaningful transition.

Friendship exists at the convergence of home, school, and recreational microsystems, thus creating a mesosystem. In this study, only the student with an acquired disability described a well-established social network. Both his autonomy and his early life experiences appeared to give him the self-confidence upon which to build enduring friendships. The students with congenital disabilities described difficult social experiences ranging from ridicule to verbal abuse and social isolation. Parents and students emphasized the importance of friendship during the transition process, but struggled to identify potential friendship partners. Future research that explores the contextual influences on friendship for adolescents with disabilities will provide valuable support for the transition process.

Exosystem: Community Facilitators and Constraints

Like the mesosystem, the exosystem is comprised of links between at least two microsystems. It is unique in that the individual need only be immediately present in one of these settings. The remote system still has a powerful impact on individual development. Clearly the facilitators and constraints
identified at the community level in this study resonate with the exosystem. Decisions that affect accessibility in workplaces, recreational venues, housing and public transportation are typically made without consulting students with disabilities. Community resource mapping is identified as a strategy to address some of these concerns (NSDOE, 2005). This can be envisioned as a layering process that begins with a student’s transition goals. The transition team then creates a map of the supports and services available within the community. The student’s strengths and needs are then superimposed on the map to identify potential barriers to meaningful transition. Nova Scotia is demonstrating a commitment to collaboration at the community level. In 2005 the Department of Education, Department of Community Services and the Independent Living Resource Centre partnered with Human Resources and Social Development Canada to develop a pilot project (Access to Community Education and Employment) in Halifax designed to promote employability skills for students with disabilities who recently completed high school. Funding for this program is tentative and program evaluation information is not yet available.

Attitudes of community members are reflected in the exosystem. The process of identifying and challenging stereotypes is daunting for families. Myths reflected in numerous interviews include: students with disabilities cannot be gainfully employed; it is too expensive to eliminate physical barriers; all students with multiple disabilities should go directly to day programs after graduation; students with communication impairments have nothing to say; and students with disabilities are a burden. These invisible attitudinal barriers are quite possibly the most disabling of all. The stereotypes about students with disabilities so problematic in the exosystem appear to originate in the broader macrosystem.

Macrosystem: Governmental Facilitators and Constraints

Individual development is acted upon by the distal macrosystem. The structure of social institutions, norms, and ideologies extant in a given culture are represented at this level. Bronfenbrenner (1988/2005) notes that the macrosystem “emphasizes developmentally instigative belief systems, resources, hazards, lifestyles, opportunity structures, life course options, and patterns of social interchange” (p.101). Governmental facilitators and constraints from this study were linked to the macrosystem. Fiscal decisions made by successive governments created extensive waiting lists for funding, housing, and support services in Nova Scotia. Although these policies were formulated at the outermost contextual level, students with disabilities felt the effects. Upon hearing that funding fell through to attend the university of his
choice, Pat stated, “I really didn’t believe I couldn’t go to [that university] and get my own apartment. That was not a good day. Let me tell you. I was already set, raring to go. I’m free!! But not yet. I will be, but not yet.”

Significant disenfranchisement of students and parents was evident. Emily provided a potential explanation for the silence of some families in the face of inequality, “And I see some of the parents, they’re not out here because probably a) they don’t have time, b) they’re intimidated, c) they need the funding.” The need for acknowledgement of student and family experiences was featured across all contexts, but particularly at the societal level. Several participants had not yet developed self-advocacy skills, others did not speak due to fears of retribution, while some were either dismissed or silenced by government officials. Empowerment at the microsystem level of students with disabilities and their families can only be experienced if barriers in the macrosystem are dismantled.

The Nova Scotia Department of Education (2005) notes that transition planning is structured by the policies and guidelines formulated by the province. Establishing a process through which the government will understand how these ideals are interpreted and enacted by stakeholders is a logical next step. Hudson’s (2006) comments regarding the dangers of a top-down approach to policy development are echoed here. It is possible that students, parents and advocacy groups were consulted during development of the transition planning guide (NSDOE, 2005); however, only people connected to school systems and government were acknowledged as contributing to the document. Including students with disabilities and their families in the ongoing evaluation and development of transition planning policy and procedures is critical. Policy must begin in the lives of students with disabilities and their families whose insights and experiences are invaluable.

Moving Toward Meaningful Transition: Participant Recommendations

While the transition experiences described by the 20 participants were diverse a number of shared experiences bound them together including the struggle to overcome obstacles, the grateful recognition of their supports, and the powerful strategies used to realize the vision each had for the future. As families described their aspirations, they spoke of their desire to create a smoother path for those who would follow. The most compelling message of all centered on the importance of finding a place to belong.

This grounded theory study supported the bioecological model of human development (Bronfenbrenner, 1992/2005). The framework presented in
Figure 1 weaves the transition experiences of students with disabilities and their families into Bronfenbrenner’s work. The contextual model offers an effective organizing structure for future transition research that moves beyond the limits of the microsystem and mesosystem to include the reciprocal influences occurring between families and the broader exosystem and macrosystem. Intriguing possibilities also exist for exploring the chronosystem as reflected in the historical roots of the transition process and as a significant event in the life course.

**Chronosystem**

Life stage aspects of the chronosystem are reflected in the recommendation that transition planning begins early — kindergarten is not too soon. Establish an ongoing dialogue among professionals, students and parents regarding what they envision for the future in terms of friendships, recreation, housing, and potential employment venues. Participants also advised that intensive educational and emotional supports be provided to students with disabilities during the transition from elementary to junior high school and from high school to life beyond the educational system. This could be accomplished through traditional venues like student support services, individual or group counselling and career planning; however, transition teams need to tailor these supports to the students involved.

**Microsystem**

The implications of an inclusive philosophy filter down into the everyday exchanges involving students who embody difference within the classroom, the microsystem. Families imagined classrooms where diverse relationships were fostered. This could mean that students with disabilities are encouraged to spend time with mentors, non-disabled peers, peers from different age groups, and with those who share the disability experience. Promoting the self-advocacy skills of families and students, particularly those with communication impairments, was also prioritized by participants.

**Mesosystem**

Recommendations involving the mesosystem focused on the school environment. Participants envisioned schools where a philosophy of inclusion was evident in the architecture, the curriculum, the friendships and the recreational opportunities. To support this shift, participants believed that school districts need to invest in life long learning for school district personnel (e.g.,
meaningful program planning, transition planning and non-violent crisis intervention). A qualitative study conducted by Neuhring and Sittlington (2003) resonates with the participants in this project. They noted that teachers need to be supported to learn more about individual students, available community options, school and government policies.

Participants also advocated for open, respectful communication with parents and students throughout the transition process. Both have a great deal at stake. Kim and Turnbull (2004) value person-centred planning; however, they incorporate it into a transition process that emphasizes interdependence. This approach offers excellent guideposts toward collaborative, respectful transition planning.

Exosystem

The exosystem clearly incorporates notions of community. Students with disabilities must have timely access to assistive technologies that can facilitate engagement within the community where young people work, live, and relax. Although concerns about access were evident, they were overshadowed by the emphasis participants placed on challenging attitudinal barriers. High school typically lasts 3-4 years, but the rest of our lives are spent within the community. We live in a society riddled with many "isms" including racism, sexism, heterosexism, and ableism. Canada is a country where we pride ourselves in being an inclusive society, yet thousands of people supported Robert Latimer’s decision to end the life of his daughter Tracy, public transit riders check their watches when someone using a wheelchair rolls on board, alternative forms of communication are dismissed, sidewalks are uneven and bullying is rampant. It is not surprising that inclusive education finds itself struggling in the translation of policy to practice. How can ableist beliefs be countered? Enhancing the critical thinking skills of all stakeholders is an excellent place to begin. For example, we might ask ourselves if disability is simply an individual problem to be remedied or if our assumptions about embodied difference may contribute to the transition constraints experienced by students with disabilities and their families.

Macrosystem

The macrosystem figures centrally in the suggestion that policy makers collaborate with students and their families. Policy review panels could be established that include the people most directly affected by the policies written by the provincial department of education, by school boards, and enacted by
school staff. Participants imagined seamless, equitable, and user-friendly procedures to support full inclusion. This can only be achieved when students and families are valued as knowledgeable contributors.

Conclusion

The Contextual Model of Transition Involving Youth with Disabilities provides a framework for students with disabilities, families, educators, health professionals, and policy makers to engage collaboratively during transition to life beyond high school. Viewing transition from all contextual levels provides the depth required to effectively support meaningful transitions. A brief review of the transition process in Nova Scotia indicated that elements of each contextual level are represented (NSDOE, 2005). The model proposed here provides an excellent framework upon which the NSDOE could organize a policy review and complete a productive program evaluation.

Mackenzie reflected on the need to look beyond the microsystem issue of diagnostic boundaries: “They’ve been doing that all along... trying to group [people with disabilities]. And I think what they have to do is mix it all together and treat it as a society rather than individual groups. Disability is disability I think... There’s certainly different names, but lot of times it’s the same thing.” Following Mackenzie’s lead, we need to acknowledge that disability exists within and interacts with all levels of our society. The model offers a framework to guide the transition process toward meaningful outcomes by revealing the complex interdependence of systems that converge in the transition experiences of youth with disabilities.

References


Paving Rough Roads


