

Adolescents with Disabilities and Chronic Illness in Transition: A Community Action Needs Assessment

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Abstract

Literature and current theory provide minimal empirical guidance to communities who must often guess at how to promote successful transitions for adolescents with chronic health and disability issues embarking on transition to adulthood. Therefore, to inform a statewide systems change effort in the State of Maine to support this population, the inquiry presented in this article was conducted. The study used an innovative, multi-method participatory action approach to ascertain the perspectives of multiple interest groups, regarding the meaning of successful transition and how to promote it in adolescents with disabilities and chronic illness. The findings revealed that interests groups held some common but many diverse perspectives. Knowledge generated from the study was used as a basis for examining the fit of the current service systems with the needs articulated by the diverse groups of respondents and informants who participated in the study, and to inform the planning efforts that are currently taking place.

Introduction

Although there are many views of what characterizes adolescent transition to adulthood, traditional scholars in the field consider majority of age, cognitive readiness, school completion and desire and capacity for independence as essential elements in their definitions and understandings of this marker event in the life cycle (Cole & Cole, 1989; Hurrelmann & Hamilton, 1996). More recently, the socio-cultural influences on adolescents in transition have been added to researchers attempts to describe and predict successful transition to adulthood (Hurrelmann & Hamilton, 1996).

Unfortunately, while adolescents with disability and chronic illness have the same desires for independence and opportunity as all adolescents (Peuschel & Sustrova, 1997), their diverse biopsychosocial growth and atypical school attendance patterns render them different than the classical and current theoretical pictures created by scholars who describe and predict successful negotiation of adolescence and transition to adulthood. Thus, literature and current understandings of adolescents provide minimal empirical guidance to providers and communities who must often guess at how to promote successful transitions for adolescents with chronic health and disability issues embarking on transition.

The study presented herein was therefore initiated by investigators in Maine who are currently in the process of revising the service system to support adolescents in transition. The findings were used as a basis for examining the fit of the current service systems with the needs articulated by the diverse groups of respondents and informants who participated in the study, and to inform the planning efforts that are currently taking place.

Literature Review

According to recent literature, adolescence is theoretically divided into three substages: early, middle and late, each characterized by physical, social, emotional, cognitive and functional elements (Burchard, 1996; Vaughan & Litt, 1990; Cole & Cole, 1989). In late adolescence youth who no longer have to negotiate significant physical changes are faced with defining their future identities (Hurrelmann & Hamilton, 1996; Vaughan & Litt, 1990). Hurrelmann sees adolescence as the primary age at which "societal dimensions of power, influence, property and prestige take place" (Hurrelmann & Hamilton, 1996, p42). Moreover, unlike non-industrial milieus, economic achievement rather than

family of origin is most influential in affording choice of social position and opportunity in adulthood. (Engel, 1989). Thus, transition into occupational roles that provide income and recognition is critical for the development of independence and autonomy in adulthood (Poole, 1989). Unfortunately, not all adolescents have equivalent opportunity and thus transition becomes particularly challenging for many groups. Among them is the large population of adolescents with disability and chronic illness (Burchard, 1996).

In excess of 5 in every 100 youth have disability and chronic illness, defined as a chronic and/or disabling condition which cause limitations in physical, social, or academic activity (U.S. Census, 1990). It is therefore not surprising that 15% of the 6.5 billion SSI recipients are persons under the age of 21 (U.S. Census, 1990). Yet, as is characteristic of comprehensive developmental theories, the experiences of youth with disabilities or chronic conditions are not addressed in this field of scholarship (Burchard, 1996), and thus their transition experiences are relatively uninformed by the developmental literature. For that reason, many researchers in the fields of special education, health and social services and disability have begun a research agenda focusing exclusively on the transition experiences and needs of adolescents who are not typical.

According to Burchard (1996), who examined self determination for persons with challenges across the life span, many barriers to successful transition exist for youth with special needs beyond the challenges faced by "typical adolescents," including limited social experience, and confusing interaction with the human and non-human environment in home communities. Further evidence revealing the transition challenges faced by adolescents with disability and chronic illness was highlighted in a recent study (1991) of more than 8,000 youth, conducted by Wagner et al. (1991) who investigated experiences of adolescents with disability and chronic conditions in three domains: education, employment and personal independence. Not unexpectedly, this group of adolescents is not homogenous and the degree to which adolescents in the study successfully navigated transition was influenced by many factors. Among them were the nature and degree of the disability or chronic illness, socio-economic, geographic and demographic factors, school attendance, service usage and efficacy of services, and family relationships. In essence, the study revealed that adolescents with disabilities and chronic conditions experienced disproportionately less opportunity than typical adolescents and were faced with fragmented and waning services as they aged out of high school.

Family issues for adolescents with disability and chronic illness also diverge from the typical theoretical shift from dependence on parents to independence and integration into non-familial social groups (Sands & Wehmeyer, 1996). Sands and Wehmeyer highlighted the conflict between over protectiveness and promotion of autonomy faced by parents of youth with disability and chronic illness. Further complicating the family picture is the dearth of services and public finances available to support and guide families in achieving a balance of safety and autonomy (Nisbet, 1992). Even when services are available, they are often prescriptive and thus do not take into account the uniqueness of individual family units.

Operating under the tenet that families themselves are in the best position to identify their needs and guide the development of relevant transition services for their adolescents and themselves, Nisbet consulted families directly in a needs assessment study relating to supporting persons with severe disabilities in community settings. The results revealed that while many stressors such as added social, personal care and financial responsibility existed, families wanted their children to be included in their home communities and would advocate for a system of flexible formal and informal supports.

As amplified by Nisbet, the service climate itself creates significant challenges for successful transition. Despite some of the new efforts that have been developed across the country, as youth age out of the pediatric health care system, services to address their special needs become increasingly scarce (Rosen, 1995). Providers who do work with adolescents and young adults frequently are not aware of the complex problems created by the addition of special needs to the typical issues faced with adolescence (Rosen, 1994; Schidlow, 1990). Moreover, adolescents who are not linked to services through special education or Section 504 may not be identified and thus do not have access to the existing services that do promote the acquisition of adulthood roles in community environments.

Recognizing the critical need to understand needs and develop community supports that enhance the transition of adolescents with disability and chronic illness, the study presented herein was conducted.

Methodology

To obtain a comprehensive understanding of the transition needs of adolescents with disability and chronic illness as a basis for future systems change in Maine, a statewide, multi-level, community-based, participatory action study was conducted. In this study the definition of adolescents with disability and chronic illness was delimited to a broad group of youth with mild, moderate, and/or severe chronic illness or disabling conditions, homelessness and mild mental illness between the ages of 14-25.

These boundaries were selected because this definition was used in Maine's enabling legislation which supported the development of formal regional groups to address issues of adolescent transition. The conditions of homelessness and mild mental illness were included in the population in that these adolescents frequently present with emotional/psychiatric and other health problems and are at serious risk for dependence in their adulthood.

A design integrating qualitative and quantitative strategies was developed to answer the following six research questions:

1. What do adolescents with disability and chronic illness, their families, providers and policy makers articulate as positive transition outcomes?
2. How do adolescents with disability and chronic illness, their families, providers, potential employers, and policy makers define independence for this population?
3. What barriers to successful transition are articulated by adolescents with disability and chronic illness, their families, providers, potential employers and policy makers?
4. What current and missing supports and services are needed by adolescents with disability and chronic illness as articulated by adolescents with disability and chronic illness, their families, providers, potential employers and policy makers?
5. What geographic, ethnic and socio-economic differences exist in articulated positive transition outcomes, definitions of independence, perceived barriers and current and needed services?
6. What differences in desired transition outcomes, definition of independence and perceived service needs exist among adolescents with disability and chronic illness, their families, providers, potential employers and policy makers?

To conduct this study, a participatory action research model was implemented (Stringer, 1996). Three methods were triangulated to conduct the needs assessment; focus groups, life histories and survey administration. This article reports the results and implications of the focus group and survey data only, since the life histories were designed to answer questions that are beyond the scope of this component of the needs assessment.

To begin the study, a statewide Steering Committee comprised of twelve representatives from adolescent (n=2), parent (n=2), health and human service provider (n=4), educator (n=2), employer (n=1) and policy maker representatives (n=1), developed the research questions and provided input on the design. Once the Steering Committee reached consensus on the methodology, the four investigators and a team of participatory researchers, herein called the Participatory Action Team (PAT) appointed by the Steering Committee, conducted all focus group activity and data analysis. The PAT, comprised of two adolescents, two parents, three health and human service providers, one educator, one employer and one policy maker, was trained in focus group methodology and facilitation, and in selected qualitative data analysis techniques by the investigator team.

Focus Group Procedures

Ten focus groups, each with six to eight participants, were conducted. To assure that the voice of each interest group was obtained, the following homogenous focus groups were convened: two adolescent groups, one parent group, three health and human service provider groups, one transition council group, one educator group, one employer group, and one policy maker group.

Recruitment of focus group members occurred by nomination from the PAT and the Steering Committee. The aim of this purposive recruitment was to obtain a range of conditions and disciplinary groups,

and a spectrum of the state's political, geographic, socio-economic and ethnic perspectives within each interest group. Once the group was scheduled, a two member team, consisting of the PAT representative of that interest group and a university researcher met with the group, obtained consent and facilitated the group. Semi-structured questions to assure adequacy of data to answer the research questions were posed to group members. All discourse was audio-taped and transcribed, with names and identifiers deleted to maintain confidentiality.

To conduct the analysis of focus group transcripts, each member of the PAT was trained in inductive and abductive analytic techniques (DePoy & Gitlin, 1998). Transcripts were independently read in their entirety by each co-facilitator and then reread for emergent themes.

Consistent with grounded theory techniques (Glaser & Strauss, 1967), each member was asked to code each datum for its fit with the initial thematic categories, then to modify thematic impressions and identify, label, and define themes. Any differences in meaning between co-facilitators were negotiated and a final agreed upon thematic analysis was developed.

To meet the requirements for determining need as articulated by the Steering Committee, quantitative analysis, in the form of content analysis to provide a ranking of the magnitude of each theme for each group was conducted by one of the investigators and is reported below.

Survey

In order to provide quantitative empirical data about service needs as perceived by parents and providers, the Provider and Family Assessment of Coordination of Care surveys (System Assessment of Wisconsin's MCH Program, 1993) were sent to a randomly selected sample of providers and parents respectively with a cover letter explaining the study and consent procedures and a request to return the completed instrument within two weeks. A total of 43 providers and 24 parents returned the survey. The rank order item, which was the same on both surveys, asked respondents to rank order the list of the services in Table 2 according to their perceived importance. These data were used to ascertain service priorities for each group and to examine differences in priorities between the two groups. Data analysis, consisting of measures of central tendency and rankings for each service, was conducted by the investigators.

Findings

Analysis of focus group data revealed fourteen themes presented in Table 1 below, none of which were articulated by all groups. The two most common themes, which emerged in four of the six interest groups, were:

1. the need for coordinated and responsive services; and
2. the need for equal post-high school opportunity for adolescents with disability and chronic

illness.

The need for coordinated and responsive services actually describes several related constructs. Essentially this theme included the need for a clear and navigable system, in which consumers would be aware of a range of services, have easy access to them, and perceive the services as useful to promoting the successful transition of the adolescents. Moreover, there was consensus that this system should be seamless and continue beyond high school graduation. Exactly what services were to be included were not agreed upon by the groups but were revealed to some extent in the other themes.

The second theme that emerged in four of the six interest groups was the desire for adolescents with disability and chronic illness to have the same post-high school opportunities as all adolescents, including higher education, job opportunity, social opportunity, independence and ultimately home ownership.

Three themes were addressed by three of the six interest groups. These were: 1. uneven and ambiguous services; 2. ambivalence towards rurality; and 3. normalcy.

Uneven and ambiguous services refer to the diversity of services and providers available as well as the degree to which those services and providers are seen as useful and knowledgeable respectively in advancing successful transition. Closely related to the theme of ambiguous services, is the theme of the limitations of rurality. While many of the participants liked elements of rural living, they specified the major limitations of availability and access to needed services and supports endemic

Table 1

Content Analysis of Focus Groups

Focus Groups*:

Adolescents	(n=6)
Parents	(n=12)
Educators	(n=7)
HHS Providers	(n=16)
Employers	(n=6)
Transition Council	(n=8)

Theme (by ranking and frequency)**:

Need for adolescents to become responsible	1 (n=26) 5 (n=11)*
Need for coordinated and responsive systems of care	6 (n=3) 5 (n=8) 4 (n=12) 2 (n=9)
Ethnic, gender, class, and geographic differences	5 (n=9) 2 (n=8)
Uneven and ambiguous service system	2 (n=15) 1 (n=24) 4 (n=2)
Limits of rurality	4 (n=11) 3 (n=4) 2 (n=13)
Ambiguity of parents (supports and barriers)	3 (n=13) 7 (n=9)
Desire and opportunity for "normal lives"	1 (n=19) 2 (n=5) 5 (n=7)
Post high school opportunity	4 (n=11) 3 (n=12) 6 (n=10) 2 (n=9)
Widespread ignorance about the needs and experiences of adolescents with disability and chronic illness	2 (n=13) 5 (n=2)
Need for accommodations	3 (n=8)
Obligation to eliminate barriers is social, not individual	4 (n=8)
Need for training and networking	7 (n=9) 1 (n=36)
Need for health insurance	1 (n=18)
Community already has assets and services	2 (n=17)

* For the focus groups, n represents the number of people in the group.

** For the themes, n represents the number of times that theme received that rank.

Table 2

Comparative Means and Standard
Deviations of Service Priorities

Item	FAMILY			PROVIDER		
	Mean	SD	Rank	Mean	SD	Rank
Developing a care plan	4.61	0.27	1	4.87	1.30	1
Obtaining financial support	4.31	0.70	2	4.71	1.69	2
Identifying services to fill a care plan	4.01	0.33	3	4.13	1.69	3
Advocacy and information	3.52	0.00	4	2.07	1.16	6
Evaluation of services to ascertain if a child's needs are being met	3.46	2.25	5	3.38	1.46	4
Evaluation of care plan	2.82	0.04	6	2.21	1.31	5

to rural areas with minimal resources. Finally, three of the interest groups spoke about the desire for adolescents with disability and chronic illness not only to have equal post-high school opportunity, but to expand this equality to all areas of life. The specific focus of this theme moved beyond opportunity to the concept of "normalcy." That is to say, participants, especially the adolescents themselves, wanted "to be like other adolescents."

Table 1 presents the content analysis of each of the fourteen themes. It is clear that each group had different perspectives and views of the meaning of successful transition and what was needed to enhance transition for adolescents with disability and chronic illness.

Quantitative analysis

In the provider and family survey, respondents were asked to rate, on a scale from 1 (least important) to 6 (most important) the need for each of the services presented in Table 2. Mean scores, standard deviations and rank orders are presented for each item.

Conclusions

Before discussing the conclusions, several limitations are noted. First, this study was conducted as a needs assessment for the State of Maine. The applicability of the results to other states thus must be cautiously evaluated. Second, because focus group methodology addresses the opinions and responses of those who participate, the findings are limited to the perspectives of the respondents. However, the applicability of the findings to broader cohorts within the state is warranted in that focus group participants were selected partly based on their capacity to represent the views of the groups to which they belonged. Third, in examining the survey results, several limitations are noted. The survey is not validated or tested for reliability. Additionally, because personal information was not obtained, there is no way of examining the differences between respondents and non-respondents.

Although there were methodological limitations, valuable information emerged from this study to inform statewide service planning. First, it is clear from the content analysis that interests groups held some common but many diverse perspectives. As indicated above, two of the fourteen themes that were revealed, the need for service coordination and the need for equal, post-high school opportunity for adolescent with disability and chronic illness, were articulated by four of the six groups. Moreover, the quantitative results informed an understanding of the nature of coordinated services that are needed. Both providers and parents viewed the development of a care plan, obtaining financial supports to enact the plan and identifying services to fill that plan as the three top priorities for service coordination. Parents identified the need for advocacy and information as the fourth priority, while service providers identified it as the least important. Evaluation of service efficacy and outcome was ranked lower by parents than by providers.

It is possible that the lack of consensus on these three areas reflects the unique needs of each interest group. The need on the part of parents to obtain for more information and to disseminate information and training about adolescents with disability and chronic illness was clearly articulated in the parent focus group. Although evaluation of services did not emerge as a concern in any focus group, the provider priority on evaluation over the parents priority on information and advocacy is understandable in the competitive climate of managed care and accountability.

Contributing to an understanding of service needs, the themes of limitations due to rurality and uneven service and informal support efficacy are noteworthy. Geographic, class, gender, family and ethnic influences over the quality of service and supports were identified by adolescents, parents and educators, and should be considered in any effort to revise and coordinate services.

The need for training and networking, articulated by providers and employers, is related to the concern on the part of parents and employers about ignorance regarding the nature and needs of adolescents with disability and chronic illness.

Somewhat related to services but broader in scope is the concern expressed by the theme of equality of opportunity. This theme, a major concern in four of the six interest groups, highlights the perception that adolescents with disability and chronic illness currently do not have equal opportu-

nity, and is consistent with the theme of the desire for "normalcy" that was expressed by adolescents, their parents and policy makers. It is possible that the desire for "normalcy" rather than a desire for recognition and celebration of the differences in this population is a response to discrimination and limited opportunity. Another possibility to explain this finding lies in the nature of adolescent development and the need to belong to a social group.

Finally, it is noteworthy that there is no consensus on the locus of responsibility for promoting successful transition. According to educators and providers, adolescents themselves should hold the responsibility for managing their transition, while parents, employers and policy makers see systemic and social institutions as the locus of change, responsiveness and responsibility.

Before discussing implications for service revision, a brief analysis of the innovative methodology of this project is advanced. The multi-method, participatory approach not only was efficacious in eliciting information from multiple perspectives and interest groups, but gave voice to populations such as the adolescents themselves who have not contributed directly to an understanding of their own needs. Moreover, the use of "subjects as researchers" in all phases of the project placed the knowledge in the hands of those who the findings would affect. Pairing a university researcher with a lay researcher provided a valuable link between the research process and those who were the "subjects" of the research and may have facilitated responses that may not have been forthcoming without that link. The use of participatory action research was not only valuable in yielding opinions and knowledge from diverse perspectives, but has provided a model for future needs assessment research.

Implications

The findings of this needs assessment have valuable implications to inform systemic revision. First, it is clear that the transition needs of adolescents with disability and chronic illness are heterogeneous and influenced by many factors. Therefore, any systemic revision should include an ongoing mechanism to study efficacy, reveal changing needs and examine how systems and supports can respond to these changes while meeting the diversity of needs in this population.

Second, it is clear from this study that providers and educators who are the traditional groups to develop and implement services may have different priorities than adolescents and parents. Service revision therefore should be orchestrated to include the needs of adolescents and parents as articulated by them. Assumptions on the part of providers and educators about what is best for adolescents may not be in concert with adolescent and parent views. A mechanism for dialogue and collaboration among all interest groups is therefore warranted.

Third, the nature of the rural environment as both a strength and a limitation is an important finding. In service planning, the unique assets of rurality such as community cohesion and safety can be balanced against the limitations such as limited transportation, access difficulties and scarce financial resources to create rural systems that are effective in producing successful transition of adolescents with disability and chronic illness.

Finally, an examination of how services can be coordinated, consistent and responsive needs to be accomplished. While services do exist, it may not be possible for these current programs to yield maximum benefits to service consumers without being well coordinated, readily accessible and consistently prepared to meet the diverse needs of the population of adolescents with disability and chronic illness.

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