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Transition Follow-up System Development for Youth with Disabilities: Stakeholders' Perspectives

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Abstract

In this study I examined in depth the perspectives of stakeholders in Manitoba on the development and implementation of a transition follow-up system (TFS) for youth with disabilities. I conducted focus groups and individual interviews with a total of 76 stakeholders and obtained qualitative data. The stakeholders who participated in this study included youth with disabilities, parents of youth with disabilities, high school special education or resource teachers, student services administrators, principals, adult service providers, government representatives, university faculty members, and advocates. The key themes identified are: the purpose of a TFS, ensuring accurate and reliable data, utilizing existing data-collection practices, government vs. non-government as administrator, multiple data collection, target population of a TFS, ensuring confidentiality and privacy, analyzing individual and program specific information, and information of interest.

This study examined the perspectives of stakeholders in regards to development and implementation of a Transition Follow-up System for youth with disabilities. The term *disabilities* in this study is consistent with the definition developed by the UN Secretariat for the Convention on the Rights of Persons with Disabilities: “long-term physical, mental, intellectual or sensory impairments which, in interaction with various attitudinal and environmental barriers, hinders their full and effective participation in society on an equal basis with others” (UN Enable, 2013, FAQ#1). In this study *transition* refers to the period including secondary education to early adult life. The U.S. Individuals with Disabilities Education Act (IDEA) defined transition services as “a coordinated set of activities including instruction, community experiences and development of employment opportunities that promote movement from school to post-secondary education, vocational training, employment, continuing and adult education, adult services, independent living or community participation” (Greene & Kochhar-Bryant, 2003, p. 55). Transition planning is a continuous and evolving process intended to deliver transition services to youth with disabilities and thus assist their transition to adult life (Greene, 2003).

A great deal of effort has been made during the last two decades in North America to help students with disabilities achieve a successful transition from school to adult life. Many jurisdictions have adopted policies that include transition services and planning as a key part of educational programming for students with disabilities and have promoted its practice. Many provinces in Canada also have provided individualized transition plans (ITPs) for students with disabilities (Alberta Learning, 2000; British Columbia Ministry of Education, 2005; Manitoba Education, Citizenship, and Youth, 2006). In Manitoba ITPs are mandatory for students with disabilities. The province's first governmental initiative to provincially address transition issues for students with special needs occurred in 1989. In that year, the province published an interdepartmental protocol on transition services, the "Transition Planning Process". In 2006, Appropriate Educational Programming in Manitoba (Bill 13) mandated transition planning and services for high school students who are 16 years old or older and require an Individualized Education Plan, or IEP (Manitoba Education, Citizenship and Youth, 2006).

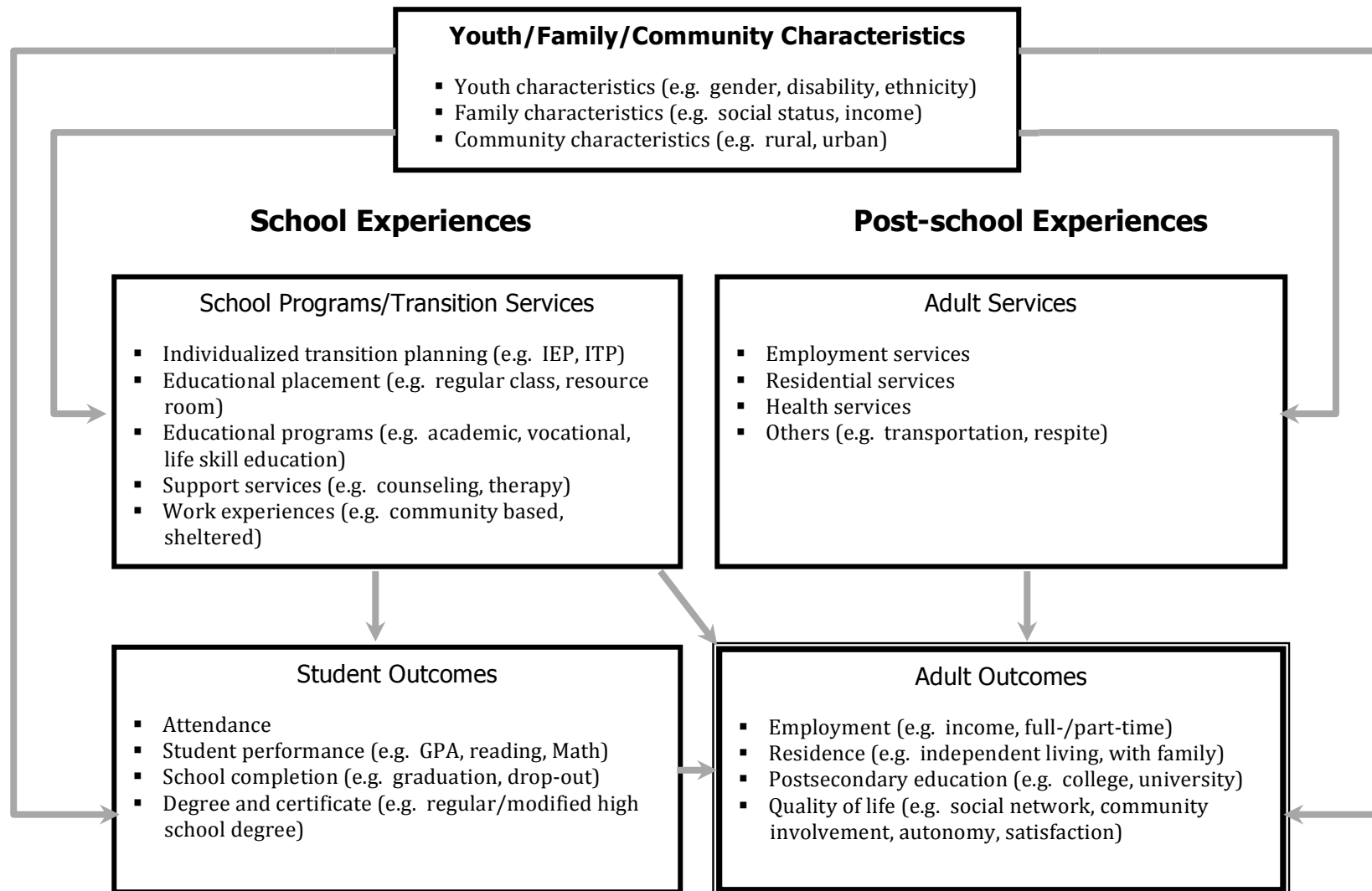
Despite the earlier initiatives of professionals and policy makers, many people with disabilities have reported difficulties in the transition from school to adult life. The post-school outcomes of youth with disabilities have continued to appear significantly poorer than those of their counterparts in terms of employment, social activities, community involvement, and independent living (Kochhar-Bryant, 2003b). The continuing challenges and poor adult outcomes that youth with disabilities experienced have raised questions about the efficacy and accountability of the current transition support system and its services (Baer et al., 2003; Benz, Lindstrom, & Yovanoff, 2000; Izzo et al., 2000; Johnson et al., 1993).

A *transition follow-up system* (TFS) refers in this study to a database system that tracks the student outcomes (educational achievements and results) and post-school outcomes (work and adult life) of youth with disabilities. A TFS can be used to: (a) measure school outcomes of students with special needs, (b) identify ways to improve educational and social services and policies, (c) ensure the accountability of programs and services, (d) provide an accurate picture of the adult outcomes of individuals with disabilities (e.g., employment, residential placement, and community integration), and (e) examine the effects of a specific intervention or system change (DeStefano & Wagner, 1992; Kochhar-Bryant, 2003a; Thurlow et al., 1998).

Researchers suggested key components of designing and implementing a TFS (Bruininks, Wolman, & Thurlow, 1990; DeStefano & Wagner, 1992): (a) conducting needs assessment, (b) developing a conceptual framework, (c) designing and selecting a sample, (d) planning for analysis, (e) developing questionnaires, (f) collecting data, and (g) reporting the results. Data collection involves a few key elements: data sources, data-collection methods, data collectors, the timeline of data collection, and response rates (Bruininks et al., 1990; DeStefano & Wagner, 1992).

In this study I examined stakeholders' perspectives on the development and implementation of a TFS in Manitoba.

Figure 1. Conceptual Framework



Conceptual Framework

Figure 1 shows the conceptual framework of this study, which is adapted from DeStefano and Wagner's (1992, p.179) "conceptual framework of transition experiences and outcomes of youth with disabilities." This adapted conceptual framework outlines the general transition process for youth with disabilities and the relationships between the key players of the process. It consists of five key aspects related to the transition process of youth with special needs: (a) characteristics of the youth and his or her family and community, (b) school programs and transition services, (c) student outcomes, (d) adult services, and (e) adult outcomes. Although each key aspect may influence the others, the arrows indicate only distinct, direct relationships between them, which have been suggested by DeStefano and Wagner (1992) and also by other researchers (Baer et al., 2003; Benz et al., 2000; Izzo et al., 2000).

Methods

In this study I conducted focus groups and individual interviews. In a parallel study I also carried out a document review, interviews, and telephone surveys on information management for persons with disabilities in Manitoba (Park, 2013). A focus group is a group interview that relies on the interaction among the participants within the group (Krueger & Casey, 2000). Focus groups and interviews are appropriate when a researcher seeks to explore in depth the perceptions of individuals or a group of people about their experiences or issues (Creswell, 2008; Morgan, 1988). Morgan highlights that through focus groups the different perceptions of the participants can be highlighted or negotiated and focus groups allow the participants to elaborate their positions, discuss related dynamics, and articulate the rationale(s) underlying their perspective. Through focus groups and individual interviews, I examined the following questions:

1. What are the needs of stakeholders for a TFS?
2. How should a TFS be administered?
3. What suggestions and concerns do stakeholders have with regards to developing and implementing a TFS?

Participants

A total of 76 persons participated in the focus groups and interviews. I recruited the participants across Manitoba with an attempt to balance the numbers of participants from urban (47 participants) and rural areas (29 participants). I carried out the focus groups and interviews with various groups of stakeholders who play key roles in the transition process for youth with disabilities. Table 1 shows the number of participants in each stakeholder group for focus groups and individuals interviews.

In this study, *youth with disabilities* are those who have had an IEP or ITP at school and have left high school fewer than eight years ago. The participating stakeholder groups had family members or worked with people whose disabilities varied considerably in type and degree. Of eight youth with disabilities, two had mental illness, two had intellectual disabilities, two had physical disabilities, and two had multi-disabilities. Two of them communicated in one or two

words for each question in the interviews. All seven parents who participated in this study were female.

The career history of the high school special education or resource teachers as educators varied from three years to 35 years. All the teachers were responsible for students with IEPs or ITPs at their schools. While most of them taught or coordinated programs only for students with moderate or severe disabilities, some worked with students having a wide range of needs. Among the Student Services administrators, all but two had been working as Student Services administrator for more than five years. The principals included three from relatively small schools (500 students or less) and four from big schools (more than 1,000 students). Three of these schools were English-centred and four were English plus an immersion program in one other language (e.g., French).

Table 1
Composition of Participants of Focus Groups and Individual Interviews

Participants by Roles	Number of focus groups (number of participants in each group)	Number of participants of individual interview	Total (N=76)
High school special education/resource teachers	2 (2,3)	10	15
Student services administrators	1 (5)	5	10
Adult service providers	2 (5,4)	7	16
Government representatives			
Manitoba Education	1 (3)	0	3
Family Services & Consumer Affairs	0	5	5
Youth with disabilities (aged 20–30)	0	8	8
Parents of youth with disabilities	0	7	7
Principals	0	7	7
University faculty members	0	3	3
Advocates	0	2	2
Total	6 (22)	54	76

The adult service providers were from agencies that supported adults with disabilities in the aspects of employment, residence, and independent living; however, most of them were from employment agencies offering opportunities including competitive employment, supported employment, and sheltered workshops. The primary disabilities of their clients included intellectual disabilities, physical disabilities, multi-disabilities, and mental illness.

The government representatives were from two departments: three participants from the Manitoba Education and five from the Manitoba Family Services and Consumer Affairs (FSCA). The faculty members were from related disciplines in universities in Manitoba. The advocates were from community organizations for people with disabilities and had extensive experiences advocating for this group of people.

I conducted interviews, as opposed to a focus group, with individuals with disabilities to better accommodate needs such as cognitive, verbal, and physical challenges. I conducted individual interviews with the representatives of Family Services and Consumer Affairs, faculty members, and advocates who are involved in the topic area (i.e., transition for youth with disabilities) due to the relatively small number of these stakeholders. With the other stakeholder groups, I allowed participants to choose to participate in an individual interview or a focus group. Each focus group included participants with similar roles.

In order to recruit participants for focus groups and interviews, I used a snowball sampling (also called network sampling) technique. Snowball sampling is an approach whereby participants are recruited by certain individuals who are in a position to recommend the most suitable participants (Creswell, 2008). In the beginning of this study, I asked some stakeholders (e.g., directors of advocacy organizations and adult service agencies, principals, Student Services administrators, government representatives, and personal contacts) to distribute recruitment letters to suitable candidates. The criteria for suitable participants were that they had been involved in the transition process for individuals with disabilities and were knowledgeable about issues regarding the transition. Individuals who had received the recruitment letter and who were interested in the study contacted me by email or telephone. All participation was voluntary.

Interview Questions and Summary Questionnaires

The participants of focus groups and individual interviews had a same set of guiding questions as the following: (a) What purpose should a TFS serve? (b) What information should be collected? (c) Who should administer a TFS? (d) From whom should the data be collected? (e) When should the data be collected? (f) How should the data be collected? and (g) How should the results be reported? The wording and components of the questions were adapted slightly depending on participants' roles and experiences related to the transition.

Data-Collection Procedures

Each focus group consisted of one facilitator and participants. As the researcher of this study, I facilitated the focus groups. Each focus group was convened for only one meeting. Focus group meetings ranged from 60 to 90 minutes.

I interviewed each participant in person only once. I arranged the time and location for each interview at the convenience of the participants, whether at their office, home, or elsewhere. The interviews lasted from 30 to 60 minutes. With the consent of the participants I made audio recordings of the interviews and focus group discussions. One participant did not want to be recorded and instead, I wrote down his answers while conducting the interview. I contacted a few participants afterward by email to obtain supplementary information.

At the beginning of focus meetings and individual interviews, I described the background of a TFS and of this research and then obtained consent for participation in this study. At the end

of the meeting, the participants completed a questionnaire (10 minutes) summarizing their perceptions of each of the interview questions. I used these questionnaires as a means of member-checking to confirm the participants' perceptions expressed during the interview or focus group. The focus groups and individual interviews generated a total of approximately 24 hours of audio data.

Data Analysis

The focus groups and interviews provided qualitative data. The qualitative data sources included the transcripts of the focus groups and interviews as well as my field notes, which contained my reflections on and observation of the focus groups and interviews. I analyzed the data, identifying common themes and discrepancies among the participants. I followed Creswell's (2008) six steps for analyzing and interpreting qualitative data: (a) organizing the data, (b) exploring and coding the database, (c) forming themes, (d) reporting findings, (e) interpreting the findings, and (f) validating the accuracy of the findings.

Results and Discussion

Based on the focus groups and interviews, I have identified nine key themes with regards to developing and implementing a TFS: (a) the purpose of a TFS, (b) ensuring accurate and reliable data, (c) utilizing existing data-collection practices, (d) government vs. non-government as administrator, (e) multiple data collection, (f) target population of a TFS, (g) ensuring confidentiality and privacy, (i) analyzing individual and program specific information, and (h) information of interest.

The Purpose of a TFS

Many researchers and professionals have emphasized the use of a TFS as a systematic tool for maintaining a data collection on the outcomes of persons with disabilities and for obtaining useful information on how to improve programs and services (DeStefano & Wagner, 1992; Elliott, Thurlow, & Ysseldyke, 1996; Kochhar-Bryant, 2003a; Thurlow et al., 1998). The participants in the present study also strongly supported the use of a TFS. As an adult service provider attested, "We collect data. We provide the data to the government. It's just the government that does not have a good system for using that data." Participants suggested that the key purposes of a TFS include: (a) to improve transition support programs and services, (b) to ensure the accountability of services, and (c) to maintain and share individuals' information.

Most of the participants emphasized that a TFS should be used to improve the services and support system for persons with disabilities. Participants noted that a TFS can be useful in determining service gaps, in identifying the factors that affect adult outcomes and best practices, and in identifying demographic trends that help the government with program planning, budgetary planning, and allocating resources. One adult service professional said,

You need to have a follow-up system to figure out whether what you are doing is working, so you can make relevant changes and you can develop it, because you can't just decide you are gonna have a system and hope that's gonna fit for every child, because that's what we've been doing so far. It isn't working.

A lot of scholars have pointed out that the follow-up and -along of individuals with disabilities is critical to ensure the accountability of services (Elliott et al., 1996; Thurlow et al., 1998). However, the participants in this study showed mixed views about using a TFS for the purpose of monitoring the accountability of services. Most participants agreed that a TFS should be used to ensure the accountability of services. For example, an advocate suggested,

We have no way of measuring, a method of evaluating school system, and transitioning system. And with the new [transition] protocol in place, I think that's good time to put something like this to monitor how we are doing for x number of years.

On the other hand, some participants, especially educators, strongly opposed that idea, suggesting that it would make stakeholders feel threatened and “monitored” and, as a result, it would discourage their participation in a TFS. This kind of response was foreseen by some scholars who noted that using a TFS as an accountability measure might cause some political challenges (Oakes, Blasi, & Rogers, 2004). The question, therefore, arises as to how to use a TFS as an accountability measure in order to improve the support system without intimidating the stakeholders.

Many participants proposed another use of a TFS, which is not strongly identified in other literature: to assist persons with disabilities and their support network to maintain and share information about the individuals. When a person with disability works with a number of professionals—such as teacher, therapist, social worker, and adult service provider—each of those professionals has a piece of information about the individual. Unfortunately, however, some participants felt that sharing the information did not occur in an effective, collaborative way. In addition, when an individual's support personnel change, some information occasionally happens to get lost in the process.

Ensuring Accurate and Reliable Data

The reliability and validity of data need to be addressed when collecting individuals' information for a TFS. Participants suggested that it could be challenging to obtain reliable and valid data for a TFS. They noted several potential threats to the reliability of the information collected. For example, “People may be answering differently when parents are in the room, when service providers are there, ‘oh, everything is wonderful.’...But it may not be always the case,” said an adult service provider. An advocate said,

When folks cannot speak for themselves and put out their own perspective out there, and share that, then the information can be quite skewed.... The teacher said ‘this person doesn't have the capacity to work’ because he or she viewed the situation. But the individuals themselves really see the situation differently.

It is critical to choose a data-collection method that meets the communication needs of the person who is providing the information. For example, if a person who has difficulty with verbal communication is to provide information by telephone, the reliability and validity of the information obtained can be significantly compromised. Most of the participants with disabilities in this study indicated they personally preferred an in-person interview as a way to offer information about themselves. Benz et al. (2000) emphasized the significance of providing clear guidelines to data collectors and of training them to increase the reliability of the data. In addition, the reliability and validity of the data to be collected can be improved by utilizing a

questionnaire written in plain language and user-friendly format, minimizing sensitive questions, and avoiding questions that rely on memory or about which the respondents may not be knowledgeable (Bruininks et al., 1990).

The vast majority of participants in the interviews and focus groups contended that a TFS should adopt a multi-data-source approach. One participant's point of view well reflects many others in this study:

To some degree that would be dictated by who you are approaching. So, if you approach the family, they might be okay with the phone interview, they might want an in-person interview if you're collecting information from individuals themselves.... So, I don't think one size fits all. You know, some folks may or may not have phone. Some folks may or may not have a level of literacy that may present some challenge with written material, some may be very uncomfortable with face to face, so I think it needs to be tailored to whomever you are collecting information from.

In addition, many participants recommended that a TFS collect different aspects of the information about individuals with disabilities from different data sources: for example, information on school programs and services from teachers, information on adult services from adult service providers, satisfaction with the services provided and service needs from individuals with disabilities and families.

Utilizing Existing Data-Collection Practices

Most educators and adult service professionals in the interviews and focus groups strongly suggested that if they are to provide information about persons with disabilities to whom they provide services, a TFS should utilize their existing data-collection practices. An adult service provider asserted,

My only concern is the amount of work. If it's built in, then I think it's achievable. If that's something brand new, and just kind of thrown at people, it doesn't make sense to what's already happening. Then, we're not gonna have a role in it.

A teacher also said,

We [teachers] are already collecting data all the time, where they [students] are at, what they are doing. So, could we then somehow funnel that information to another source where we don't need to do the work twice? We already have that information in IEPs.

Many educators and adult service professionals in this study contended that incorporating their data-maintenance practices into a TFS would reduce additional work and that it might make the TFS more efficient. In addition, some educators suggested that a TFS set up an online database into which schools can easily incorporate data from IEPs or ITPs and many others strongly supported the idea. A teacher said, "It [developing an online database based on IEP or ITP forms] would kill two birds with one stone and would also be a more standardized format. Then, the expectation is certain information being collected. Yeah, then we would do it."

Government vs. Non-government as Administrator

One of the most distinct themes that I identified in this study was the involvement of the government in conducting a TFS. Some participants expressed concerns about the government's

administering a TFS, suggesting that a neutral body, such as independent researchers, run a TFS because the government's own interests might taint the reliability of the data collected. An advocate confided, "With the government, I don't entirely trust them. And I think the information can be skewed." A participant also argued,

They [the government] are likely to start to collect and interpret the data in ways to support whatever programs that they think they are good at... But what they are not so good at, people get masked, because it's in their own best interests. So, I think it should be at arm's length.

A teacher added, "For government, it's just long for anything to take place and so much red tape and paper work. I just think too rigid to be able to work together. It would be harder."

By contrast, many other participants recommended that a government body run a TFS because of the advantageous position of the government in securing financial resources, controlling confidentiality of a large amount of information, connecting a wide range of stakeholders (e.g., persons with disabilities, families, school, service providers, government programs), and having actual power to make changes in policies and the support system. An adult service provider suggested,

Possibly that should be through Family Services [Manitoba Family Services and Labour] because they are the ones that are involved with the individual, other than their parents, for the longest period, whether it's Children's Special Services or adult services. They [the government department] are the ones there consistently. And they are the ones who could probably ... they can keep it ongoing, if it needs to be monitoring a longer period after graduation.

Another participant said,

Obviously this [TFS] is gonna require some robust computer hardware and software and manpower and likely some sort of facility, those things. How effective could it be if there're constant funding struggles? With the government doing it, that may be less of a problem.

It was also pointed out that without the government's involvement, it might not be feasible, or at least much more challenging, to engage all schools and government programs in the process.

Multiple Data Collection

Most of the studies that have examined adult outcomes of persons with disabilities have gathered school information with post-school information after the individuals left school (Izzo et al., 2000; Kochhar-Bryant, 2003a). Researchers have cautioned that as the length of time between school leaving and collection of school-related data increases, the accuracy of the data tends to decrease. This is because those who provide information rely more on their memory or old documents (Johnson et al., 1993). In Manitoba, schools are encouraged to begin individualized transition planning for students with disabilities at age 14 (Healthy Child Manitoba, 2008; Manitoba Education and Training, 1998). Some participants proposed to begin data collection at the age of 16 for individual students, whereas others proposed starting at the age of 14. Perceptions of the participants on the period for data collection varied from three years after school to lifelong.

Many researchers recommend that adult outcomes be tracked more than once, noting that follow-along procedures help better examine the relationships between services provided and

outcomes (Greene & Kochhar-Bryant, 2003; Johnson et al., 1993). A number of participants supported multiple data collection, stressing the significance of tracking an individual's transition process from school to adult life. A youth with disabilities said, "I think it should be more than once at least for the first few years [after high school]." A parent argued, "Once would be more like a snapshot than ongoing understanding of where the individual is. Plus, people change, they grow, they develop, some folks meet developmental stages." Some participants argued that multiple data collection would help prevent them from falling through cracks of the support system by identifying their support needs and issues more frequently. Given that schools and adult programs usually update their service plans for their students or customers yearly, some participants argued that annual data collection might be adequate. While expressing concerns about the additional work to school personnel that the data collection might cause, some teachers and principals agreed that if teachers were to incorporate the information in students' IEPs or ITPs into a TFS, as opposed to gathering new information for the TFS, multiple data collection for school information might not be too great a burden to teachers.

Target Population of a TFS

Participants agreed that it makes sense that a TFS tracks individuals with disabilities whom the education and social service systems identify as requiring extensive support needs and about whom the systems maintain information as regular practice. Those individuals include students with an IEP or ITP and adults with disabilities eligible for the government adult programs in the province. Furthermore, participants emphasized that the target population of a TFS should include individuals with disabilities outside of the support system: adults who have had an IEP or ITP but have not received any services from the major government adult programs, and those who have not had an IEP or ITP but have required an adult service. A participant argued,

I know that there's gaps in services for kids with behavioral needs—autism, FASD [fetal alcohol spectrum disorder], and that kind of stuff. So, there are right now no programs for those kids. If we are not carrying on that data, then there is potential to lose information on those individuals.

Some participants noted that tracking information of those out of the support system is important to identify gaps in the support system.

A problem exists with including in a TFS adults with disabilities who are outside the adult support system. It may be difficult to track a large number of such individuals unless their participation is mandatory. Some participants were more optimistic, saying that some adults with disabilities who do not receive support from the government may still be motivated to participate. This may occur, for example, if they see the TFS as a tool for improving the support system and for identifying their service needs. Without obvious incentives or benefits to them, however, many of these adults may not be willing to provide their information to the TFS.

Ensuring Confidentiality and Privacy

One of the key aspects related to TFS, which participants emphasized, was protecting the confidentiality and privacy of individuals with disabilities. An educational administrator's comment well summarizes many others' concerns:

I think the information, the more is the better. But also, it needs to [be on a] need-to-know basis. So, it's a fine balance in terms of what you need to know, how much you need to know, and who needs to know it.

In addition, the administrator of a TFS should ensure the security of the data collected in the process of data collection and management. Despite the existing Privacy Acts (e.g., the Freedom of Information and Protection of Privacy Act, the Personal Health Information Act) in the province, a number of participants expressed a concern that it could be challenging to follow the Acts while collecting and sharing the information of individuals with disabilities (Manitoba Government, 2010). It was also stressed that special caution must be paid to ensuring that individuals make an informed decision when releasing their personal information for a TFS.

Analyzing Individual and Program-Specific Information

Many participants recommended that participation in a TFS be mandatory and that a TFS track information of all eligible individuals with disabilities, as opposed to taking a sample. Sampling is a cost- and time-efficient approach that allows researchers to identify trends of a large number of people with a small number of representatives (Bruininks et al., 1990). A youth with disabilities argued, "The person should have the option whether or not to do it, whether they should get tracked or not." Supported by many others, however, a participant disputed, "If it's left voluntary, I think, some people would be on board, but then you would have fragmentation again. I think it should be universal." Also, some participants argued that the involvement of schools and other service agencies in TFS should be mandatory. An educational administrator contended,

It shouldn't be your choice whether you want to complete it or not. It should be an expectation that schools would provide that and mandate whatever agencies taking on data collection. I think it should be a part of the program.

If a TFS is to examine collective information of a large number of individuals with disabilities, its goals may be met by taking a sample of the population. In fact, the vast majority of follow-up studies for persons with disabilities and existing TFSs aim to identify general trends or factors. However, participants in this study maintained that case-specific information about individuals with disabilities would be as important as collective information, if not more so. Case-specific information is particularly useful in tailoring services and programs on a need-basis. A teacher, for example, said,

Any kind of information that I can have about my former students would help me in my planning with my current students. For students on the similar path, if that's going really well, I might think it would be good for upcoming students and make it as recommendation in our planning process. And if it wasn't something working well, I'd probably use that information too.

In addition, a lot of participants—individuals with disabilities and parents in particular—argued that many persons with disabilities fall through the cracks after leaving school and that a TFS should be used to ensure their stability in life and smooth transition from school to adulthood. It is contended that tracking individual-specific information would help to achieve this. If a TFS takes a sample of the population, it would fail to provide individuals with disabilities and their support network with case-specific information.

Information of Interest

Participants agreed that TFS results would be useful to their own stakeholder groups (e.g., individuals, families, educators, service providers, the government). Some participants suggested that the reporting of TFS data be tailored to their audiences based on their needs for certain information. The professionals who support individuals with disabilities in the transition process (such as educators and adult service providers) noted that they would appreciate information on the historical outcomes of their programs and on the individuals for whom they provide services. An adult services provider said,

We [service providers] need to look at our own programs and whether things are having an impact, which is a real struggle for an agency. We are providing service, is it effective? If it isn't, why are we doing it, let's stop. And hopefully, this [TFS] would provide data for us in terms of whether or not what we are doing has some positive impacts on outcomes.

A service provider observed, "Because you are running a program within your agency, you think you're meeting the needs, but you only have this small picture of folks that you are seeing." He added that TFS data would allow service providers to "see where you are in benchmark." Such data would allow them to evaluate their own performance, analyzing successful strategies and to see where they are in benchmark compared to others.

Many participants suggested that the government would benefit from statistics on the demographic trend, gaps in services, and needs for services. A representative of the government noted,

It would be useful for us [the government]...if we were to do planning along this way, know the number of individuals, what they want to do, and what they need generally. Then, we would be able to plan services and it would give us some tools to do that.

In this study individuals with disabilities and their families asked that a TFS provide information that could guide decision-making about individuals' future options and also information that can be used for self-advocacy. A participant with a disability suggested,

I think the disability community as whole could benefit from that [TFS]... that [TFS data] gives them something to work with to go, say "Hey, you know what, these are the areas need improving, let's start working on that." That gives me something to work with.

Conclusions

The key results from this study are summarized as follows:

1. Stakeholders requested that a TFS produce information that can help not only the improvement of the support system for youth with disabilities in the transition process on a macro level (e.g., province-wide), but also all the stakeholders involved on a micro level (e.g., school-wide, agency-wide, individual-specific).
2. The key suggestions that stakeholders made with regard to implementing a TFS are (a) ensuring impartial, reliable data management, (b) minimizing any additional work required for schools and adult services programs and agencies, (c) utilizing existing data-collection practices, (d) applying various data-collection methods, (e) carrying out longitudinal data collection regarding individuals with disabilities, and (f) protecting privacy and confidentiality.

3. The most significant concerns and barriers that stakeholders expressed with regard to developing and implementing a TFS in Manitoba were about the capacity (e.g., funding, human resources, time) of the government, schools, and adult programs/agencies to establish and also to maintain a TFS.

In order to realize a TFS in Manitoba, I recommend that the Manitoba government initiate a pilot project that tests the feasibility of the proposed TFS model and refines the model as required.

There is very limited knowledge about perceptions and needs of stakeholders (e.g., persons with disabilities, families, professionals, government, etc.) in regards to assessing outcomes of persons with disabilities (i.e., what information to collect, how to gather data, and how to use the data collected). This research generated knowledge about the perspectives of stakeholders as to how to develop and implement such a model.

There are some limitations that need to be taken into account when interpreting the results of this study:

1. The results of this study are based on the Manitoba context and, therefore, may not be applicable to other parts of Canada, which have different history, culture, support system, and regulations.
2. The participation of stakeholders in Northern Manitoba was limited. Given that the culture of Northern Manitoba is distinctive from the southern regions of the province, the results of this research may not reflect the needs of the northern region regarding a TFS.
3. This study had limited representation from certain groups of stakeholders in focus groups and individual interviews. For example, only few persons with moderate or severe intellectual disabilities or with sensory impairments participated in the study. In addition, the majority of the adult service professionals who participated in this study were from employment service agencies, with fewer from residential or other adult service agencies.

One topic that I have identified as not being well researched in existing literature is the transition period for persons with disabilities. Although numerous follow-up and follow-along studies investigated post-school outcomes of persons with disabilities, very little is known about how long it takes for persons with disabilities to settle down as an adult after leaving high school. Hence, I recommend research that investigates the criteria that determine the adjustment to adult life and that examines the typical length of time it takes persons with disabilities to adjust to adult life. The period required for the adjustment to adult life can be a critical benchmark of post-school outcomes. Such data would be useful for the support system in planning for programs and services required and for individuals with disabilities and their support network to set a realistic timeline to make progress.

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