

In Transition: Experiences of Parents of Children with Special Needs at School Entry

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Abstract Pre-school children with special needs face a complex transition to school, requiring additional administrative, social and educational support. In this study, parents of 40 children with special needs reported on the transition to school experience of their 4–6-year-old child. They completed a measure of impact of the child's disability on their family and an assessment of the quality of services experienced. Individual, semi-structured interviews contextualized these evaluations. Twenty children (pre-transition) were in preschool; 20 had already started school (post). Post-transition parents reported less average disability impact on family, generally lower perception of quality of care than pre-transition ones, and long waiting periods for school-based support. Most parents, however, reported satisfactory linkages between prior-to-school services and school. In conclusion, this study demonstrates that, despite the current climate of support for early child development, barriers for satisfactory transition to school still exist, and are largely due to low effectiveness of existing policies.

Keywords Children with special needs · Transition to school · Quality of services · Linkages

Introduction

The transition from pre-school to kindergarten is an important and complicated event in any child's life. When the child in question is affected by a disability, this transition becomes even more complex and challenging. In the United States, 3.5% of children under 5 years of age are reported to have disabilities (National Center for Health Statistics 2006); the corresponding number in Canada is 1.6% (Human Resources Development Canada 2003). In both countries, this proportion more than doubles among school-aged children: in the US to 8.5% of the population, and in Canada to 4.0%. Among the Canadian children with disabilities, 96.3% attend school, most of them enrolled in regular classes. While inclusion is a goal, if not the standard, for education of young children with special needs, the process of transition from home or preschool to a regular classroom is fraught with difficulties (Janus 2004).

The success of transition to school for a child with special needs depends very strongly on the availability of supports at school to facilitate the child's learning. Issues like lack of specialised personnel or programs are among those that most frequently generate complaints from parents of students with special needs (Valeo 2003). In a large community sample, a third of parents of kindergartners with special needs were not satisfied with the transition of services, and close to half were not satisfied with the availability of school-level services for their child (Janus et al. 2007). Few studies empirically investigate the issue of parental involvement and advocacy, however, most research related to transition of children with special needs

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strongly recommends that parents get involved in the process in order to ensure that their child receives adequate support (Fowler et al. 1991; Duncan 2003).

Lack of linkages between various sources of services has often been listed among the reasons for poor transition experience both for children with special needs (Fowler et al. 1991; Wolery 1999; Shotts et al. 1994; Rous et al. 1994), and for the normative population (Early 2004; Janus 2004). Information collected from parents, albeit largely retrospectively, indicates that assessments are often duplicated, paperwork is overwhelming, and communication between various agencies practically non-existent. Most of these investigations recommend policy changes to facilitate communication and linkages among the agencies involved in the care of children with special needs.

Early childhood issues, including those related to children with special needs, have been receiving increased attention in Canada over the past several years. Within this context, many local jurisdictions and school boards have established a detailed set of policies guiding the assessment of needs and the transition to school practices for children with special needs (Janus et al. 2007). The task of facilitating linkages forms part of the mandate of agencies providing care for these children. In view of these more recent developments, it became necessary to determine empirically whether the earlier findings noted above, which were based on studies conducted 10 years before, and in different contexts, would continue to hold true in the current situation.

This study was carried out in a major urban centre, where a number of supports, procedures and policies exist for parents of young children with special needs, both for the pre-school children, and at the school entry level. Nevertheless, there has been only anecdotal evidence so far regarding the transition process from the prior-to-school, comprehensive services to school-based ones. Our study, which included parents of children in the pre-kindergarten year, as well as those of children already in kindergarten, had a two-fold purpose. It was designed to (1) assess differences in parental perception of the quality of care and the impact of disability on their lives between the families prior to transition and those who had already experienced transition to school, and (2) identify the links in services experienced by parents during the transition to school. Both quantitative and qualitative data were collected. Considering that the literature is fairly consistent in reporting that parents find transition both frustrating and unsatisfactory, we hypothesized that parents of children already in kindergarten would experience higher impact on family and less positive processes of care than those who were not yet at school. In view of the exploratory character of this study, the analyses of the linkages are largely descriptive.

Methods

Participants

Parents of children with special needs were eligible to participate in the study if their child was between the ages of 4–6 years, and was either in the first year of kindergarten, or would be entering kindergarten the following September. The designation of “special needs” was defined using the guidelines for exceptionalities as set out by the Ministry of Education of Ontario, Canada, with the exception of the classification of “giftedness” (Ministry of Education 2000). This definition includes disorders which affect the child’s behavioural, communication, intellectual, or physical abilities.

Participants were recruited primarily through the main regional hub for treating children with special needs: posters about the study were distributed in clinics, and various allied health professionals at the centre were informed about the study and asked to notify parents. However, since the centre has patients with a broad variety of ages and conditions, and this study had a very specific age focus, it was necessary to supplement the recruitment through a variety of different avenues. Recruitment efforts were extended to attract more subjects and several contacts were made in the community. An organization whose mandate included caring for or supporting young children with special needs, mailed out flyers to its list of parents of children with special needs. Flyers were also distributed to child care centres in the area, and a network of integrated resources. Once the family contacted the research assistant, the study protocol was explained to them. This involved an interview with the parent/caregiver, and completion of several questionnaires. Only one eligible family declined participation at this stage. However, it has to be noted that only interested families contacted the study, so it is not possible to ascertain the exact response rate.

In total, 40 families participated in the study: twenty of those had a child who was already in kindergarten, and 20 had a child prior to school entry. The demographic characteristics are in Table 1. Boys outnumbered girls in both

Table 1 Demographic characteristics of the two study groups

	Pre-transition Group	Post-transition Group
N	20	20
Boys	17 (85%)	16 (80%)
Respondent’s education: some post-secondary or higher	14 (70%)	14 (70%)
Respondent’s source of income: employment	14 (70%)	13 (65%)
Two-parent family	17 (85%)	17 (85%)
Median income	\$40,000–\$49,999	\$40,000–\$49,999

groups 4:1, and both groups had parents with very similar education and income. Of the 40 children in the sample, 16 (40%) had no clear diagnosis. The majority of the remaining children had multiple diagnoses.

Measures

Impact on Family (IOF)

The Impact on Family (IOF) Scale is a 27-item scale which measures a parent's perception of the effects of their child's chronic health condition on family life (Stein and Jessop 2003). Originally developed to measure four different domains (Financial, Familial/Social, Personal Strain and Mastery), the IOF scale also provides a Total Score and is a valid and reliable measure of the social and familial impact of chronic childhood illness.

Measure of Processes of Care (MPOC)

The Measure of Processes of Care (MPOC-20) is a 20-item scale which measures parents' perceptions of the actions of health care professionals. It was developed to examine the way in which care is delivered and the impact of service delivery on children with disabilities and their families (King et al. 2003). It is a self-administered parent-completed questionnaire, and has five scales: (1) Enabling and Partnership (EP), (2) Providing General Information (PGI), (3) Providing Specific Information about the Child (PSI), (4) Coordinated and Comprehensive Care for Child and Family (CCC), and (5) Respectful and Supportive Care (RSC). This measure has been determined to have good consistency, reliability and validity (King et al. 2003).

Vineland Adaptive Behaviour Scales (VABS)

The Vineland Adaptive Behaviour Scales (Sparrow et al. 1984) are a measure of adaptive skills, and are administered in an interview with parent/caregiver. The items comprise four subscales: communication, daily living, socialization, and motor skills. There are specific norms developed for individuals with disabilities.

Severity of Condition

Parents were asked to rate the severity of their child's condition on a scale from 1 to 6, where 1 indicated low, and six a high severity.

Interviews

In addition, an interview was conducted with the parent to collect qualitative data on the child's current or anticipated transition to school. The interviews were conducted in the family's residence, or in the research assistant's office based on the parent's wishes. Interviews were rescheduled as many times as was necessary to accommodate the families.

Analyses

Descriptive statistics and mean comparisons were calculated for the scale scores of VABS, IOF and MPOC-20 for post-transition and pre-transition groups. In addition, the effect sizes for differences between groups were computed for the IOF and MPOC scales.

Five aspects of the transition experience were assessed based on the interviews. For the pre-transition group, these were: (1) whether the school has been contacted, (2) who initiated the contact, (3) what information was exchanged, (4) what the parents' expectations were, and (5) whether there were plans for school-based treatment. For the post-transition group, the aspects were: (1) services involved in transition, (2) who initiated the contact with school, (3) when the first contact happened, (4) whether there were any communications with previous services, and (5) the current status of school-based communication and services. This information was described and quantified where applicable.

Interview information for two children, both in the post-transition group, was omitted from analyses. One child was admitted to Junior Kindergarten in the fall prior to the interview and 2 months later effectively expelled with the recommendation that she start in Senior Kindergarten, thus not entirely fitting either the pre-transition or post-transition question structure. The other child was a twin sibling of another one in the sample. While all the other measures were completed on both children, it was not possible to conduct an interview on each, and therefore one child was selected randomly for the interview. Therefore, the total sample size for interview data is 38, with 20 in the pre-transition, and 18 in the post-transition group.

Two researchers coded all 38 interviews, one of them doing it twice for test-retest reliability. Percent agreement was calculated to reflect the major coding (i.e., yes vs no), and minor coding (i.e., subcategories within the "yes" category). The major category percent agreement varied from 89% to 100%, and minor category from 60% to 100% for inter-rater reliability. The corresponding ranges for test-retest were 89–100% for both categories.

Results

Impact on Family

Parents of pre-transition children reported significantly more impact on family in social-familial and personal strain domains than parents of post-transition families (Table 2). The effect sizes for these two differences were 0.79 and 1.02, respectively. There was also a moderate difference between the two groups in financial strain.

Processes of Care

Parents' perception of the quality of care they were receiving differed between groups (Table 3). While none of the differences reached conventional levels of statistical significance, parents had consistently more positive perceptions of the care in pre-transition group. The effect sizes of the differences were generally moderate in size.

Adaptive Behaviours and Severity of Condition

Post-transition children had statistically significantly lower adaptive behaviour skills than pre-transition children (Table 4). This happened despite the fact that the post group was older than the pre-transition group. Parent rating of children's condition severity was significantly higher for the post group (mean 4.6 vs. 3.65, $F(1,38) = 5.414$, $P = 0.025$).

Contact with School

Pre-transition Group

Very few of the families had not made the contact with the school at the time of the interview. In 17 out of 20 cases, a contact had been made. Services involved with the child had reportedly recommended the contact, but in 11 cases, it was initiated by the parent. The day care resource teacher or current service providers did so for three children, and it

was unclear for the remaining three. Of the 17 families who contacted the school, most (8) had only a verbal contact, 4 had an upcoming meeting, and 6 already had a meeting of some sort.

Post-transition Group

Three families reported that they had no contact with school prior to transition. Among the remainder, in the majority of cases (9) the parent had initiated the school contact. For two families the first contact happened in the fall of the year prior to the child's school entry; for 8 families it happened in the spring or summer, and five could not recall exactly the time. In the great majority of cases (16/18), the principal or other representatives of the school board were actively involved in transition of children to school. In more than half the cases (14), a day care staff, usually the resource teacher, was also involved.

Exchange of Information

Pre-transition Group

Among the 17 children whose parents made contact with the school, there was no exchange of information on two of them. Paperwork from previous services was passed on to school for five children, and in one case the information was passed on verbally. Parents of four children stated that the information will be shared, and parents of five said that perhaps information will be shared.

Post-transition Group

Parents of nine children reported that no communication between school and previous services occurred since the beginning of the school year; two were unsure. Of the eight parents who reported that there was some communication, three said it was a written exchange, two reported a meeting, and three were unspecified.

Table 2 The means, standard deviations and effect sizes of difference between pre-transition and post-transition families on the domains of the impact on family questionnaire

Impact on family	Means		SD		Effect size	P-level
	Pre-transition	Post-transition	Pre-transition	Post-transition		
Financial	6.1	4.4	3.35	3.41	0.50	0.139
Familial/social	16.4	11.3	6.44	6.53	0.79	0.022
Personal strain	10.3	6.0	4.23	4.43	1.01	0.005
Mastery	11.4	10.4	2.96	2.60	0.34	0.288
Total score	44.1	32.0	13.15	13.19	0.92	0.009

Table 3 The means, standard deviations and effect sizes of difference between pre-transition and post-transition families on the domains of the Measure of Processes of Care (MPOC)

MPOC domains	Means		SD		Effect size	P-level
	Pre-transition	Post-transition	Pre-transition	Post-transition		
Enabling and partnership	5.2	4.8	1.58	1.42	0.22	0.49
Providing general information	4.8	3.8	1.70	1.52	0.57	0.095
Providing specific information	5.6	4.8	1.54	1.82	0.49	0.179
Coordinated and comprehensive care	5.5	4.7	1.29	1.66	0.58	0.131
Respectful and supportive care	5.6	4.8	1.36	1.48	0.61	0.084

Table 4 The means, standard deviations and effect sizes of difference between pre-transition and post-transition families on the domains of the Vineland Adaptive Behaviour Scales (standardized scores)

VABS domains	Means		SD		Effect size	P-level
	Pre-transition	Post-transition	Pre-transition	Post-transition		
Communication	77.1	58.6	20.75	24.78	0.89	0.016
Daily living	69.4	50.3	17.42	18.71	1.10	0.003
Socialization	73.3	60.0	14.72	16.32	0.90	0.011
Motor	67.1	49.1	20.80	19.28	0.86	0.011
Composite	66.4	48.5	17.13	16.66	1.04	0.002

School-based Treatment

Pre-transition Group (expectations)

Eight families were uncertain as to what type of treatment may be planned for their child. Four expected none. Only one family reported plans for school-based treatment only, three reported that there might be both school-based and some external treatment for their child, and four families reported that the plans for future treatment involved only external service providers, one of whom planned to engage private services (as opposed to hospital or pre-school).

Post-transition Group (current status)

Parents of three children reported to have received all the treatment/support they needed from school, while parents of four reported to have received none. One provided no information. For the remaining 10 children, at least some support was reported, e.g., having an Educational Assistant (EA), but not a speech therapist, or having access to transportation but not the EA. Seven children had an EA in the classroom, with two parents expressing concerns as to the quality of this service (in one case the child had 6 EAs in 6 months; in another mother thought the EA did not have specific training for her child's needs). Parents of 8 children stated their child did not have an EA. For the remaining five the issue was either not relevant or the information was not clearly stated.

Discussion

In this study, we expected to find that parents would consider the transition to school a stressful process, leading to higher impact on family and lower perception of processes of care among those whose children were in kindergarten than among those prior to transition. Only some of our expectations were confirmed. As hypothesised, parents of children already in school reported less positive processes of care than those whose children were in the pre-transition stage. However, parents of children in the pre-transition stage consistently reported higher disability impact on the family, in particular in the personal strain area and social/family life.

A comparison of the means for the MPOC-20 scores showed consistently lower means in all five domains for the post-transition group when compared to the pre-transition group. While not statistically significant, four out of five differences reached a moderate effect size. Since, for the most part, health care services become the responsibility of the school board upon transition to kindergarten, these results suggest a decreased degree of satisfaction with the child's new health care services. The findings from interviews seem to support this possibility. While most children were receiving at least some school-based services, only three children were receiving all the required services and supports, and half did not have access to an EA. Interestingly, this reality is to some extent also reflected in the reports from parents of pre-transition children. Only four mentioned that there were plans for school-based services for their children, while the majority was

either hoping to continue with the current services or uncertain as to the plans.

Much of the frustration experienced by the post-transition parents was likely associated with the school board's delay in implementing resources promised to the parents at meetings prior to school entry. Since the school board appears to be aware of the need for special resources prior to school entry, it is probable that the problem lies within administrative practices rather than overall lack of resources. The school board should also consider the manner in which they promise these services to parents. Providing parents with a more realistic idea of what their child can expect upon entrance to kindergarten may prove to minimize the amount of frustration experienced by parents during this period of time.

Lack of communication between services used by children prior to school and the school system has been found before to be one of the major barriers to successful transition for children with special needs (e.g., Wolery 1999; Fowler et al. 1991; Rous et al. 1994). In their practical guide to connections between community, family and school, Kraft-Sayre and Pianta (2003) recommend a creation of a distinct committee or dedicated position for a person to coordinate the transition. One of the most positive findings in our study was that the crucial partners were, more often than not, involved in the transition process: Resource Teachers from day cares contributed to reports sent to schools, and often participated in the intake meetings. Even post-transition, about half of the participants reported some communication. These findings suggest that the channels of communication were open and working.

Administrative issues that include availability of staff to do the paperwork surrounding the transition process, and to provide adequate school-based support have also been previously identified as barriers (Wolery 1999; Janus et al. 2007). Many children in our study did not have access to qualified support staff right from the start of the school year; over half did not have access to an Educational Assistant. Reports from pre-transition parents also clearly indicated that the majority of them were uncertain and apprehensive about the outcomes at the beginning of kindergarten.

Contrary to our expectations, we found that parents of post-transition children reported significantly less impact on family than the parents of pre-transition children, with the largest differences in the personal strain and social-familial domains. Since their frustration with the process of transition and in many cases the status of supports available from school was obvious, judging from the MPOC scores and interviews, it is likely that the IOF measures different aspects in relation to family experience - perhaps not relevant to the experience of the process of transition. For example, the social-familial domain contains items

pertinent to not seeing family and friends, and not having time nor desire to go out; the personal domain contains items about stress and fatigue. Both these areas could be positively affected by the regularity of the child's school attendance. Studies show that more stress is experienced by parents of children with special needs than by those of typically developing children, and although all parents must sacrifice their time for their children, parents of children with special needs often have to make greater sacrifices (Kazak and Marvin 1984; Ray 2003). For this reason, having a child transition to school may provide some relief in terms of stress by allowing the parents time for themselves and the opportunity to become involved in other activities. The moderate effect on the financial strain domain may have been due to the fact that many parents pay out of pocket for preschool or daycare for their children, whereas once their child transitions to kindergarten, they no longer have to pay as much.

The size of the sample in this study was an obvious limitation. Also, our two groups were not even in terms of the developmental severity of their needs. This could have influenced the comparison of MPOC scores: since the children in the post-transition group were perceived as being more severely affected by their conditions, they probably also required more services, and hence parents' perception of care could be lower. Both composition and severity in a community sample of children with special needs are characteristics that are virtually impossible to control. Nevertheless, our investigation highlighted some new and important themes. We found that communication between pre- and school services was not much of a problem, suggesting links were being made between services involved in health care and education of children with special needs, at least for the intake purposes. However, the quality and efficiency of these links remain questionable. Parental reports indicate less than 50% rate of fulfillment of promises of support made prior to transition. As well, the quality of services, once the child enters school, is perceived as lower than prior to transition.

The results of our study suggest that parents perceive that attention is being paid to the transition to school for children with special needs. However, this attention is more effectively translated into action at the pre-school level, with the involvement of day cares, resource teachers, and services. While school-based personnel also appear to be involved, parents' experiences indicate that this is not effectively translated into action towards a timely delivery of supports required by children.

In conclusion, although the current political climate supports policies to assist children with special needs, parents' perspectives captured in our study demonstrated that there is a gulf between a policy and its effective execution. Transition is an "in-between" process that is not

owned by any one agency (Janus 2004), and therefore an assessment of its effectiveness, based on the perspective of parents only, cannot be conclusive. Further investigations are needed to establish whether the effectiveness of communication, linkages, and supports in the transition period promotes a more successful adjustment to school among children with special needs, (a goal valued by parents and educators alike).

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