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Managing Continuity of Care for Children with Special Needs in rural and Remote Parts of Northern Ontario

October 2005

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Key Implications for Decision Makers

Rural residents place a premium on being able to access care in or near their home communities. As long as they can have professionally guided care, the benefits of staying home outweigh the possible advantages of direct professional therapy, if the latter is only available in a city.

A viable system of care is created when the same team of health professionals travels to rural communities on a regular basis to develop care plans that are then implemented either by unpaid mediators or paid paraprofessionals who are local residents.

While both the mediator and paraprofessional approaches work, paraprofessional caregivers are preferred by clients because they deliver services in a constant and consistent manner.

Moreover, their therapeutic work is monitored by regulated health professionals.

Maintaining the better approach — using paraprofessionals — requires a sustained investment by government. It is difficult to attract individuals who are qualified unless full-time, long-term contracts can be offered.

Continuity of care is influenced by the model of service delivery, certainly, but also by staff turnover, referral routes, waiting lists, and the motivation of clients.

Delivery models based on integration of interdisciplinary teams that cross agency and sector boundaries foster continuity of care.

Executive Summary

Achieving continuity in managing the healthcare of rural residents in northern Ontario is made difficult by two facts — the distance between communities and the scarcity of health professionals. A provincial initiative, designed to meet the special health, mental health, and learning needs of rural children in the region has tried alternate ways to overcome these barriers and ensure that clients have access to services in or near their home communities. Interdisciplinary teams of health professionals, employed by the Integrated Services for Northern Children program, travel to rural communities as consultants to assess and develop care plans that can be implemented by non-professionals who reside locally. The latter fall into two categories: “mediators” (such as education assistants or parents) who work with a specific child on a volunteer basis; or “intervention workers,” paid paraprofessionals specially prepared to work with children that have specific needs; they normally have several clients on their caseloads.

Managers for the program in the Thunder Bay District, in partnership with researchers at the Centre for Rural and Northern Health Research and The Centre of Excellence for Children and Adolescents with Special Needs, compared the continuity in the process of care achieved using each method. Data were collected through (a) reviewing a random sample of 327 client charts; and (b) a series of semi-structured in-person interviews with 100 individuals, both clients and providers, involved with the program. Six questions were posed.

To what extent do clients remain in contact with Integrated Services for Northern Children program services? Although people accepted professionally guided care by mediators because it was delivered locally, they much preferred the intervention model because the workers were able to maintain a consistent routine, often seeing their clients twice a week. Consequently they

could react more quickly to changes in children's needs and regularly seek advice from the professional members of the team. In mediation cases contact is maintained but not as frequently; the professional resource team usually visits once every six weeks.

To what extent are there breaks in the delivery of services? Some 45.6 percent of clients' charts record a substantial time gap in services, but this statistic must be interpreted cautiously. The intervals may be warranted by a child's clinical status, or due to client's non-attendance. However, interruptions also occur because professional or paraprofessional staff leave, creating delays until replacements are found. Difficulty recruiting bilingual speech/language and mental health workers has caused significant breaks in the services available to some francophone children.

To what extent is there continuous contact with the same care providers? Client files show that most children have the same caregivers for extended periods. In mental health cases changes may occur as clients explore therapeutic options. Most changes are associated with staff turnover, however. In the case of professionals leaving, these disrupt the mentoring/monitoring relationship with paraprofessionals.

To what extent are plans of care implemented? Client charts show distinct differences, with mediators almost twice as likely not to implement care plan recommendations and to encounter barriers more often, perhaps because they are less able to navigate the health and education systems. Mediation plans are reviewed annually, while intervention plans are continuously updated. Interviewees noted that concern about overburdening parents limits the extent of mediation that can be expected, while parents engaged more actively when they had regular contact with an intervention worker.

To what extent is there co-ordination with primary care services? The focus was on family physicians. Smaller rural communities often lack adequate physician coverage; given their expected “gate keeper” role, this creates delays in the referral process to medical specialists. Because intervention workers are in constant contact with professional consultants, situations requiring medical attention are spotted and referrals made earlier than in mediation cases.

To what extent is there co-ordination with formal and informal caregivers? The program’s dual approach involves both; all individuals concerned are included in case conferences, but information is also routinely exchanged between parents and case managers or intervention workers. These local workers were relied on as spokespeople for parents’ concerns, especially at school.

The findings show that paraprofessionals can provide certain health services successfully and, where professional providers are limited, they extend the capacity of the health system’s human resources. In the case of rural communities, the availability of local workers diminishes the need for residents to travel to access care. As long as they can have professionally guided care, the benefits of staying home outweigh the possible advantages of direct professional therapy, if the latter is only available in a city. The preferences for and strengths of the intervention model in terms of continuity are evident; this component of the program deserves ongoing funding from the province. Moreover, with modifications, the intervention worker model is likely transferable to other health and social service programs in rural areas.

Context

Managing continuity in the care provided to residents of the rural communities and small industrial towns scattered across northern Ontario is a significant challenge because of the realities of service delivery in the region — a vast, sparsely populated area with widely distributed case loads, where it is difficult to attract and retain professionals outside of the few urban centres. For example, in the District of Thunder Bay, where the non-urban population of 41,498 lives in an area twice the size of Nova Scotia, there are no rural-resident psychiatrists, pediatric specialists, or psychologists, only two speech/language pathologists, and two occupational therapists. The present study examines alternate strategies adopted for a major provincial initiative to overcome this human resource deficit and allow people to access services in or near their home communities. Although the focus is on one client population — children with exceptional health, mental health, and education needs — there is potential for the delivery model to have broader application.

The Integrated Services for Northern Children program is a joint effort by the Ontario ministries of Children and Youth Services, Health and Long-Term Care, Education, and Northern Development and Mines to meet the special needs of children in the region's rural areas or small towns. The program's service model relies on interdisciplinary teams of city-based professionals, known as the resource group, who travel regularly to sites throughout the north to provide assessment, consultation, and some treatment. Case managers, who reside in the communities, act as the single point of entry and co-ordinate these services. As originally conceived, continuity in the care provided depended upon volunteer "mediators" (such as parents or teachers) implementing the intervention plans developed for clients by the resource group professionals. However, in response to concerns of parents and schools about the consistency of care and the program's ability to ensure compliance by unpaid mediators, the District of Thunder Bay Integrated Services for Northern Children program began to employ its own discipline-specific paraprofessionals: occupational therapy/physiotherapy intervention workers; behavioural intervention workers; and speech-language intervention workers. This step was paid for partly by small supplementary program grants, awarded on a year-by-year basis, but mostly through accumulated budget surpluses.

The Thunder Bay District program managers, in partnership with researchers at the Centre for Rural and Northern Health Research and Centre of Excellence for Children and Adolescents with Special Needs, wanted to determine which approach provides greater continuity in managing care. Specifically, comparing the use of "mediators" and "intervention workers," the study asked: (1) *To what extent do clients remain in contact with Integrated Services for Northern Children program services?* (2) *To what extent are there breaks in the delivery of services?*(3)

To what extent is there continuous contact with the same care providers? (4) To what extent are plans of care implemented? (5) To what extent is there co-ordination with primary care services? and (6) To what extent is there co-ordination with formal and informal caregivers? These questions reflect the six dimensions of continuity in the care process set out by Johnson, Prosser, Bindman, and Szmukler (1997).

There are two groups of decision makers in the program — local and provincial — for whom the issue of alternate delivery models *vis-à-vis* continuity of care is important. At the local level, the site management committee of the Thunder Bay District program is interested in the link between the use of paraprofessionals or mediators and goal achievements; the blending of paraprofessional and professional strategies; and increased options for care. At the provincial level, the inter-ministerial management committee and the assistant deputy ministers' committee for the program, representing the stakeholder ministries, are responsible for evaluating the program's performance and overall program policies. The ministries are seeking evidence of best practices with respect to service delivery, as well as to have issues affecting services identified. Financial constraints introduced while the study was underway added to the study's significance for both decision-making groups, however. At the start, one intervention worker's salary was being paid by the annualized program grant, while five others were funded through accumulated surpluses and transfers within the Integrated Services for Northern Children program itself. This changed; surpluses, already reduced as professional positions were filled and salaries increased, could no longer be retained from one fiscal year to the next. Consequently, the number of intervention workers decreased while data collection was ongoing; a fact reflected in the findings.

Implications

Residents of outlying communities are generally satisfied with the services their children receive, expressing particular confidence in the program's professional consultants. While they much prefer the intervention worker model when it comes to implementing care plans, they accept mediation because it means that treatment still occurs in the community. As long as their children have good, professionally guided care, the benefits of staying home outweigh the possible advantages of direct professional therapy usually only available in a city, either Thunder Bay or Sault Ste. Marie. The reasons for this are clear. It takes hours to travel from almost all of the smaller places in the district to one of these urban centres. Not only is this expensive, but the children often lose time from school and their parents have to take time off work. Moreover, in winter the roads can be treacherous.

The realities of service delivery in the north are shaped by other factors as well. The scarcity of professional mental and other health services, common in rural areas across North America

(Heyman and Vandebos, 1989), is compounded in the case of children by difficulties recruiting and keeping child specialists and inadequate support services (Kelleher, Taylor and Rickert, 1992). One solution to the scarcity of professionals is to involve paraprofessionals and volunteers, to whom rural people have greater access (Blank, Fox, Hargrove and Turner, 1995).

Paraprofessionals can be employed where there is insufficient professional staff, but also where a new sort of worker is required to fill a service gap (Fuller, 1995). Examples of the latter are the Aboriginal health workers found in all northern Ontario First Nations (Katt, Kinch, Boone and Minore, 1995). Informed by the northern Ontario experience, DuBois, Nugent, and Broder (1991) proposed a model wherein mental health services for children in underserved areas are offered through a network of community-based providers. One key to achieving this “multiplier effect” is the maintenance of appropriate links among providers in the community and between them and outside professionals (Boone, Minore, Katt, and Kinch, 1997).

The present research supports these ideas. Evident to an extent in quantifiable differences between “mediation” and “intervention,” such as the specificity of goal-setting, actions taken on therapeutic recommendations, and impediments to implementation, it is clearer still in the opinions expressed by those who are directly involved with special needs children. The benefits they identify are numerous. One cluster relates to relations with clients, both children and their parents. Paraprofessionals are able to establish consistent routines that encourage faster goal achievement by their charges. In addition, because contact is frequent, activities are easily modified to suit changing needs. It seems that parents, who often lack the time or skills to intervene themselves, become more engaged when an intervention worker is involved in their children’s care. They feel comfortable turning to the worker for advice, and rely on them for support in their dealings with the healthcare and education systems.

The other cluster of benefits is an outcome of the professional/paraprofessional relationships within the program team. Contact occurs on a weekly basis, allowing for a continuous review of their shared caseload. Moreover, the paraprofessionals’ practice is enhanced by ongoing mentoring and supervision from regulated health professionals. Both groups achieve an understanding of one another’s competence and respective roles in implementing the care plans.

This ideal is challenged by staff turnover in either category. Such changes rupture the trusting relationships established with children; it takes time for new caregivers to build these relationships. Moreover, because their ranks are thin the team may temporarily lose coverage in a specific discipline when a professional leaves. Similarly, the loss of one intervention worker often affects a number of children in a given locale. Recruitment of replacements can be difficult,

not only for professionals, but also for paraprofessionals. In the latter case, if there are no suitable candidates locally, it is hard to attract someone with the required skills from elsewhere, because the program lacks funding to offer full-time contracts.

The preferences for and strengths of the intervention model in terms of continuity are evident. Yet funding for this component of the program is discontinuous, lurching from year to year. If the model works it needs to have sustained funding as part of the Integrated Services for Northern Children program's core budget. Otherwise a desirable service delivery method is not viable. This, perhaps, is the most obvious implication from the research. However, the findings also show that paraprofessionals can provide certain health services successfully. By doing so, in situations where professional providers are limited, paraprofessionals extend the capacity of the health system's human resources. This applies to northern Ontario and similar rural areas across Canada. Hence, with modifications, the intervention worker model is likely transferable to other health and social service programs.

Approach

The study was carried out, principally, in six rural Integrated Services for Northern Children program access sites across the District of Thunder Bay, which at the outset shared a case load of 586 children. Data were collected through (a) a review of a random sample of 327 client charts; and (b) a series of semi-structured in-person interviews with 100 individuals, including a random sample of 35 parents/primary custodians of the children included in the chart-review sample, the 11 resource group professionals, the eight members of the site management committee in the City of Thunder Bay, 12 local care providers (case managers and intervention workers), and a random sample of 34 of the 42 non-custodial mediators.

The university-based members of the research team did a systematic chart review limited to children receiving care within the period from July 1, 1995 to December 31, 2001. The cases were stratified according to the type of continuity management used and by the category of need (communications disorder, occupational/physiotherapy, or behavioural/mental health). There were 55 cases in each sub-sample, except two; of the occupational/physiotherapy cases, only 54 mediation cases and 53 cases involving an occupational/physiotherapy intervention worker met the inclusion criteria.

The charts incorporate both the records of case managers and those of the resource group professionals. As well as specifying treatment outcomes, the client files detail the expected processes to achieve these target outcomes. The purpose of this review was to assess adherence to the plans of care; however, it did not assess treatment outcomes. There is mounting argument

that continuity is an aspect of the process of service delivery which should be measured separately from client outcomes (King, Rosenbaum, and King, 1995; Brugha and Lindsey, 1996; Kluiters, 1997; Thornicroft and Tansella, 1999). This is especially true where something new is being tried. Process measures can “be used to investigate whether innovative service developments alter service delivery in the intended ways” (Johnson, Prosser, Bindman, and Szmukler, 1997, p. 137). Further, such measures may be “more appropriate to stated service objectives than measures of individual patient outcome” (Bindman et. al. 2000, p. 246). As explicit assessment criteria, the chart review tool used the markers set out in the program’s intervention model, which maps the expected progression of cases within the system. In brief, the model tracks clients from community/parent referral; assessment by resource group; development of service plan; assignment to mediator or intervention worker; referrals (other agencies) or cross-referrals (within the program); evaluation of service status; modification of plan; client discharge; and/or follow-up plans.

Adopting a specialized strategy sometimes referred to as elite interviewing, in-depth interviews with professional and paraprofessional members of the health team, parents/custodians, and non-custodial mediators yielded extensive qualitative data. The interview phase began after the chart review was completed; the interviews were used, in part, to explore issues that emerged from the review. In addition to the written notes taken during the interview, the interviews were recorded by audio tape for later transcription. A sample of the consent form which participants were required to sign is included in appendix A and the interview guides are in appendix B.

Johnson, Prosser, Bindman, and Szmukler (1997) identified six dimensions to maintaining continuity against which the process of care can be tested. These dimensions formed the basis for the study’s research questions. They also constituted a list of what Patton (1990) refers to as “sensitizing concepts,” which were used to organize the chart review and interview data. The analysis focused on recurring concepts and their relationships with one another (Morse and Field, 1995). In sum, both qualitative and quantitative data generated were categorized by two models of care, three categories of need, and six dimensions of continuity: (a) continuity of service provision (whether clients remain in touch with the service); (b) breaks in service delivery; (c) continuity of contact with particular providers; (d) implementation of plans for services; (e) co-ordination with primary care services; and (f) co-ordination with formal and informal caregivers.

The Thunder Bay program manager played an ongoing role in conducting the research: guiding the research assistants and overseeing their work during the chart review stage, which was done at the program’s office; helping to formulate the interview questions; systematically analysing the resulting data with others on the research team; and reviewing this report in draft.

Results

The results are considered here under each of the six dimensions. The first is encapsulated in the research question: *To what extent do clients remain in contact with Integrated Services for Northern Children program services?* The answer we found depends on a number of factors; the model of care, certainly, but also the types and components of service, as well as the motivation of both parents and children.

The loss of intervention workers in certain specialties and sites while the study was underway threw into high contrast the continuity of contact possible when the program could use community-based staff, rather than relying on volunteer mediators. Clients that had been seen twice a week by intervention workers now had an appointment once every six weeks with the visiting professionals. The loss was keenly felt. One case manager recounts “I’ve been in the street and been yelled at by a parent ‘who do you think you are?’ because the intervention program was pulled.” Other parents, while accepting the situation, remember “having direct intervention and that was a whole lot better.”

The intervention workers were able to establish a routine, so they saw their clients on a regular basis. Parents found that “it was consistent and constant and the kids were achieving things a little quicker.” The frequent contact allowed the workers to quickly modify activities to accommodate children’s changing likes and dislikes. Moreover, because the workers lived nearby, parents felt comfortable calling them about any concerns. For their part, resource group professionals appreciated the monitoring that resulted. “The intervention worker would let us know weekly if there was a problem as far as the parent wanting to continue or problems with transport, stuff like that” one said, adding that the frequency of feedback had declined with the increased reliance on mediators. Client charts show some quantifiable differences as well. In cases involving an intervention worker, for example, when clients missed a consultation there was follow-up contact 81 percent of the time. This number slips to 66 percent when the program is relying on a mediator to implement the care plan.

For the most part the new reality has been accepted, albeit resignedly. One non-custodial mediator concluded, “. . . to have anybody coming at all, I guess we’re fortunate.” Those in the mediation stream understand that the program offers professional consultation rather than regular therapy. However, the frequency of contact is a concern, especially among school staff. An educational assistant summed up a discussion among her colleagues that concluded the visiting professionals “observe [children for] a half hour... they don’t see the whole... any given day they’re getting a

different picture.” This occurs when there is an intervention worker, of course, but it is offset by the established connections between professionals and paraprofessionals.

Professionals in the resource group agree that such intervals can occur. “You might need to do an assessment [but] by the time you get there and by the time you do the report and the programming suggestions; a lot of time can sometimes go by.” Urgent cases also bump non-problematic ones from the visiting professionals’ schedule, thereby lengthening the period between contacts for some clients. The need to visit all communities on a regular basis limits the extent of adjustments that can be made. That being said, the professionals accommodate clients’ needs as much as possible. As one said, this means “I’m doing appointments from 8:00 in the morning until 9:00 at night and going to homes, schools, offices so there will be a lot of flexibility.”

There was strong consensus among non-custodial mediators and parents that the program’s staff is accommodating and accessible. The barriers to access created by distance are being overcome by technology. They can contact program staff using a 1-800 number; this is seen as a vital option. They can also participate in video- and teleconferences. “It’s not the same as being in person, but still it’s better than waiting another two months,” said one. Ultimately, most are appreciative of the services offered, realizing the constraints that distance, as well as fiscal and human resources, impose on the frequency of contact.

Clients, themselves, also determine the extent to which contact is maintained. This applies whether intervention workers or mediators are involved. The program alternately relies “on parents to get kids... to appointments with therapists and intervention workers,” or, in mediation cases, on “parental involvement to carry through with recommendations on an ongoing basis.” Such engagement requires that care objectives and priorities are communicated clearly.

The second selected dimension of continuity is reflected in the question *To what extent are there breaks in the delivery of services?* It is clear that such breaks occur; 45.6 percent of clients’ charts show at least one substantial time gap. This fact requires careful interpretation, however. In many cases these periods are warranted by the child’s clinical status at the time. Sometimes, too, the services are interrupted because of client non-attendance. In other instances, the disruptions are linked to staff turnover, the availability of individuals with the required knowledge, or waiting lists to see professionals in certain disciplines. An annual break is built in; the program aligns with the school year, so there is a hiatus in many activities during the summer months. While some parents felt this hampered their children’s progress,

experience has shown that families' summer plans make it impracticable to maintain a full range of services in July and August.

A pattern of behaviour on the part of clients accounts for some of the recorded breaks in service. Certain children are chronic no-shows whose parents "call a day later and say 'oops.'" Because of the length of time between resource group visits to a community, several missed appointments mean that considerable time passes between contacts. Similarly, mediation efforts are hampered when children do not attend school regularly.

Albeit an exceptional situation, one community had three case managers in a two-year period. Turnover in staff disrupts services. Recruitment is often a slow process, so months may elapse before a position is filled. When the right person is found, he or she has to be oriented to the position and the clients. One parent observed that "they're always coming in new so they're having to get caught up on the child's history and their educational needs... so [it] takes a lot of time to get everything back in place." Similarly, changes in teachers and educational assistants affect students reliant on school-based mediation. Not only is time lost, there is a strong and widely held opinion that the detrimental effects of the delays are compounded by a failure on the part of the new educators to familiarize themselves with their charges' case files.

The lack of professionals in certain disciplines, or paraprofessionals with specific skills, also serves to block continuity. For example, at the time of data collection the program did not have a speech pathologist on staff. A school-based respondent complained "I had someone on the speech list, [then] I find out nobody is taking over [the speech pathologist's] spot, so that poor little one's going to sit on a wait list somewhere." The unavailability of services shows up in clients' charts; in 35.6 percent of intervention cases and 51.2 percent involving mediators, a recommended service is not accessible in the client's home community. Bearing in mind that the professionals developing care plans are aware of local resources, these figures likely understate the need for certain services.

Respondents in all categories mentioned the lack of professionals and paraprofessionals able to speak French as an impediment to good continuity. Although the proportion of francophone clients is small, there are communities in the District of Thunder Bay where French is spoken by a substantial part of the population. Consequently there is a need for French language services, which are difficult or at times impossible to provide. In one case, a family moved after three years: "They never had any services because there was no francophone worker, and these two kids did not speak enough English for them to see [anyone else]."

Speech/language and behavioural interventions were identified as areas where there was a particular need for bilingual services.

Of course, lengthy periods of time on waiting lists can break the continuity of care. In this regard rural children are no worse off than those who live in the City of Thunder Bay; indeed they may fare better because they have a designated program through which they can access services. Still it may take several months to see a speech pathologist, teacher diagnostician, psychometrist, or an urban-based medical specialist such as a pediatrician, orthopedic surgeon, or psychiatrist.

The program's role as a single point of entry to services was expanded in 2002 to include allied programs in child development and children's mental health; this move has both advocates and critics. It is seen, on one hand, as a way to improve co-ordination and avoid duplication of services. On the other hand, it is characterized as creating a new barrier. In the view of one professional, the "wait is now at intake... because there is not enough staff for the abundance of work coming in" for various children's services. First scheduling and then doing intake meetings, each of which takes a couple of hours, inevitably slows the process down. A mental health worker provided an example. "When someone would walk into our office before and say 'my kid got suspended from school and they won't let him go back [until he gets] counselling' we would book him the next day. That doesn't happen anymore." The single point-of-entry issue emerged as a particular concern when respondents were asked about breaks in the continuity of services.

Johnson and his colleagues (1997) argue that care by the same person is a measurable indicator of continuity. Hence, the question *To what extent is there continuous contact with the same care providers?* The clients' charts indicate most children continue to work with the same caregivers for extended periods. In most cases where changes occur, it is noted that a particular professional, paraprofessional, or non-custodial mediator is no longer affiliated with the program. Sometimes, as well, a change is made at the request of a client.

Client-initiated changes are common in behavioural cases. A case manager reports that requests for another therapist "happen in mental health all the time... all the time... back and forth." It is accepted that parents want the best for their children and may want to explore all therapy options or, in other words, to "try everyone's style and technique." This is not the only reason, however. When it comes to caregivers, small communities face a unique *challenge of familiarity*. Because people know one another and are often related, clients may be concerned about confidentiality being maintained, despite the assurances of professional standards. "If so-and-so's sister works as a counsellor, they may want to request somebody else."

The number of professionals working in each program area is small, so the departure of one person can affect a large portion of the cases in a specific discipline across the region. Similarly, the loss of intervention workers affects a number of children locally. Yet the program is constrained by its inability to offer full-time, permanent contracts to intervention workers. There may not be any qualified candidates living in a given community; those from elsewhere are not going to relocate for a part-time position. Funding limitations compound the problem: “They have a hard time finding people to take those jobs and they have a difficult time keeping people... [there is] not enough money.” In the mediation model, changes in caregivers are inevitable as children progress from grade to grade when teachers or educational assistants act as mediators.

Provider turnover has various consequences. Clients build trusting relationships, which encourage progress and facilitate communication. These are temporarily disrupted when new players are introduced. A school-based non-custodial mediator summed the situation up, saying “They just kind of get comfortable with somebody and then, if it’s somebody new... especially the kids I work with... you’re almost back to square one.” It takes time for new workers to build rapport, particularly since many special needs clients do not adjust well to change. Staff turnover also affects the extent to which people access program services. Usage declined, for example, during the intervals between case managers in a couple of communities.

The loss of professionals has a further detrimental effect in cases involving intervention workers. Because the latter work under the supervision of regulated health professionals they are able to perform delegated tasks. This relationship lends credibility to intervention workers’ practice, of course. But it means the intervention worker model is fully functioning only when there are professionals available to perform the oversight role. In contrast, a mediated process is affected less; parents or education assistants have materials prescribed in the plan of care with which they can continue to work.

Various strategies are adopted to help clients accept the departure of familiar caregivers and adjust to ones who are new. If there is a failing in the transition phase, it is in letting mediators know before the fact. Often they became aware of the departure only when the replacement arrives. A parent complained of getting a letter introducing a new staff person that said “Hi, I’m so-and-so, I’m the new case manager... and you wouldn’t even know [before] the other person was leaving.” Non-custodial mediators in the school system had similar reactions.

When comparing the continuity achieved by intervention workers and mediators, respectively, a key question is *To what extent are plans of care implemented?* In this regard, chart data are

instructive. First, because the approaches are fundamentally different, goal-setting is an explicit part of mediation plans much less often (20.1 percent) than it is where an intervention worker is involved (67.9 percent). Second, it appears that specific suggestions or recommendations made by the resource group were not acted on in 29.2 percent of mediation cases, compared to a 17 percent in intervention cases. Third, mediators more frequently encounter barriers to implementation; 61.7 percent compared to 40.5 percent of intervention cases note one or more impediments. It is not surprising that the incidence is high for both, given the challenges of services delivery in a rural area, but the lower intervention number likely reflects that fact that program staff are able to negotiate the system more easily on behalf of their clients.

All care plans are reviewed at least once a year, with adjustments made to suit the client's situation. In this regard, the contrast between the two models is striking, however. A resource group professional said of the annual review that "[the] mediation model is more of a one-time thing... [there is] certainly not the same kind of follow through... it's not as dynamic." In the intervention model, because "the therapist reviews client progress with the intervention worker weekly... [they] revise and adapt them as they go."

The development of the plans is an inclusive exercise, involving any professionals, paraprofessionals, or non-custodial mediators who will work with a child, as well as the parents and child themselves. The contents are therapy-driven, based on recommendations contained in consultation reports, but reflect the available resources along with the capacity and wishes of the clients. In their interviews, the resource group professionals, case managers, and intervention workers all saw themselves as responsible for implementing the plans. Individuals acknowledge the role of other players; for example, a member of the resource group states "goals are reviewed with the intervention worker [who] carries through with activities to try and achieve those goals." Another said "the intervention worker probably has a better relationship with the teachers and the parents than I would myself." However, regardless of their position, individuals assigned the lead to themselves or their profession. Another member of the resource group, when asked who keeps the plan going, said "Probably me — I'm the one that decides how long the treatment will be... but I always consider input from the school, and home and the intervention worker."

Parental participation varies. One case manager mentally divided her files into three approximately equal piles: those where the parents are "self-motivated, consistent, and able to follow through on their own;" those whom "I could honestly entrust with a responsibility ... and I wouldn't have to do much hand-holding;" and finally those who can only "handle minimal responsibility... with... hand-holding, prodding, [and] encouraging." Parents themselves generally report that

they were consulted and kept informed, but that they relied on the professional expertise of program staff for guidance. The level of parental involvement depends on their situation. A single mother of four was hard-pressed to help her child diagnosed with attention-deficit hyperactivity disorder. It also depends on the individual. One mother whose child had an intervention worker said “I think it’s important... if you don’t do things at home with them, then [intervention] really doesn’t work.” But another admitted to being overwhelmed by the expectations she felt her son’s mediation plan put on her. “To be honest with you. . . I just didn’t get it done because it was just adding to the school work I was already doing with him.” Caution about overburdening parents in this way becomes a limitation when mediation plans are set. The goals have to be clear, not too complex, and achievable. Members of the resource group felt that parents of children with intervention workers engaged more actively because of the regularity of contact with the program’s staff.

In fact, the intervention program was first initiated in part because parents could not provide the treatment required; they lacked the expertise and they lacked the time. “Not every single goal would be achieved by kids in the intervention program, but every single goal at minimum showed progress,” in the opinion of a member of the site management committee. It is harder for the professionals to monitor progress where the mediation model is used, according to one resource group member, because contact is less frequent and “you’re always relying on other people for information.”

The program invests heavily in distributing written material that supports implementation of children’s care plans. These are almost universally welcome, by both school staff and parents. Indeed, they are seen as essential by members of the resource group. “It is a lot more helpful to the parents and the teachers if they can see something on paper... to understand a little bit better what the recommendations are and entail.” Of course, to be useful the materials have to be written in language that is comprehensible to a lay person.

A degree of tension exists over school staff participation in implementing the care plans. While educators felt they were consulted during the development phase, at least a few did not feel they were kept informed about any changes. This viewpoint underscores a situation that is tricky for the program, because it is the parents who control the sharing of information. Some neglect to advise the school; others do not wish to do so. In either case it is beyond the control of the program. The other contentious issue arises from school staff turnover and a perceived tardiness on the part of newcomers to inform themselves about the content of relevant assessments. One parent remonstrated “The new teachers need to be told ISNC is doing a job the same as you are... you

expect me to read your report cards, then read theirs and maybe you'll understand the kid." The schools are expected to play a major role under the mediation program but were seen as following through fully only half of the time. That being said, some school-based mediators felt the need for more direct help from the program. "It would be nice if the teacher diagnostician or person who does the educational assessment could come back for more follow-up, because they only [give] one feedback." Moreover, parents concerned that program recommendations are not being followed at school believe the program should be monitoring this more closely.

Co-ordination among caregivers is essential for continuity to be achieved. The research looked at co-ordination from a number of angles: within and between agencies, in the specialist referral process, and between the formal and informal systems of care. The first co-ordination question asked *To what extent is there co-ordination with primary care services?*

Respondents identified a number of categories of primary care practitioners on their roster of referrals, but focused their attention on family physicians. "ISNC acts as a liaison between mothers and doctors... [it] is a lifeline to sanity for [mothers] that can connect them to professionals they need." However, there are problems when no family physicians are practicing in a community, something which occurs periodically in smaller places. The fact that primary care physicians play a "gate keeper" role in terms of accessing some specialist services can also be problematic. For example, referral to a pediatrician can be done only through a primary care physician. Similarly, mental health cases get "backlogged because of the process of going through a family doctor and then to a specialist... and then [on to] a waiting list." In intervention workers' cases, less time is lost simply because of the constant contact between them and the resource group professionals. The weekly telephone monitoring of case loads gives the professionals early warnings of symptoms that may require medical attention. These might not come to light as quickly where mediation is involved. In either model, however, the resource group professionals may bypass the normal referral process, using their own affiliations or network of contacts with specialists to access care for their clients "because it is easier."

Another important issue is the nature of feedback received from both primary care and specialist physicians. In some instances, nothing is shared; a child's medication may be changed, but the program is not informed about the change, or there may be lengthy delays in receiving information. One case manager noted "unless doctors have very proactive nurses, it can be hard to [get timely] reports from physicians." Parents also complain that test results were simply sent in the mail; interpreting the clinical findings or understanding terminology used can be difficult for a lay person.

The availability of a primary healthcare service locally also determines the ease of co-ordination. Routine eye examinations are a case in point. The Eye Van, a mobile eye care unit, regularly visits smaller centres across the district. But a town that experienced a sharp population increase when a nearby mine expanded suddenly lost the service; with 4,416 residents, it was considered too large. The local case manager notes “it is more difficult to have client’s eyes checked now that the Eye Van no longer comes to the community.”

The program’s dual model approach involves both formal and informal caregivers. Therefore, the last research question is critical for gauging the continuity achieved: *To what extent is there co-ordination with formal and informal caregivers?* There is consensus that case conferences occur regularly for both intervention and mediation clients, and that these include all of the people who need to be there. Talking about one situation, a non-custodial mediator said “[It] was an incredible experience to see that many people being concerned about one child and working together to solve issues that arise, and I think it was really great for the parent.” There is information-sharing and a chance to understand one another’s roles. As well, these meetings “clear the air sometimes between professional people and the parents and the school as to what’s actually happening.” Information exchange between formal and informal providers is not limited to planned meetings, however. Case managers call intervention workers and parents to check on progress, and parents said that they would stop and talk to the workers when they ran into them in the street.

Intervention workers noted that parents were welcome to take part in their activities with the child, but that generally “it was difficult to get parents on board.” Nonetheless, one of the benefits parents ascribed to intervention workers was having them as spokespeople to bring parental concerns forward within the circle of care. “Just having that intervention worker there to take some of that load off” helped parents, according to one case manager. A parent whose child had an intervention worker echoes this view. When the parent had concerns about a school placement, she reports the worker said, “if you need me to go to the school, I will go and be there with you... and she was there supporting me throughout.”

A number of parents expressed frustration about their interactions with the school system, feeling that the school was not implementing the recommendations of outside professionals or, conversely, trying to implement a type of programming which the parents did not want, such as putting their child in a special education class. Program staff members were seen as intermediaries, able to translate the wishes of both the parents and the school to one another. A member of the site management committee said “Often parents and the school agree on what they want the final goal to be, but they don’t agree how they are going to get to that goal.”

Case managers are committed to helping parents understand their rights in dealing with the school and other topics that affect their children's well-being. For example, they go over the results of assessments with the parent and encourage them to ask questions. If there are things that the case managers can not explain, they are able to quickly find the answer from the professionals who prepared the report. This is a byproduct of the "open relationship between our case managers and our resource team," a rapport fostered by regular meetings of the interdisciplinary network involved.

Involvement of staff from other agencies further benefits the process. It also allows clarification of mutual expectations and identifies overlaps or gaps that may be occurring. Numerous instances of co-operation are identified. For example, a mediation parent was confident if they called family services that, in turn, the Integrated Services for Northern Children program would be advised, because there "seems to be a good correlation [sic] between family services here and ISNC." But inter-agency co-ordination is not always good. For example, when a child is also a client of mandated services, confusion can arise from having multiple case managers or, as one said, "too many cooks in the kitchen."

On balance it appears that co-ordination with formal care providers follows well-established patterns. Referrals are made when clients reach the age of 18 or when a family moves to a new community, either within or outside of the District of Thunder Bay. Similarly, for those on the client list, referrals to specialists are made in a timely manner. This does not necessarily mean prompt attention, however. Waiting lists slow the process for certain professions, like psychiatry, although one non-custodial mediator, acknowledging the health human resource deficit, said "that is the reality of living in the north."

Two potential studies are suggested by the findings. The first was anticipated at the outset; having examined the impact that *process* has on continuity of care, the clinical *outcomes* should now be assessed. When considered on six dimensions of continuity, using intervention workers was clearly favoured over the mediation model for implementing plans of care. It is hypothesized that these differences will be reflected in client outcomes as well, further supporting the argument for investing in the intervention approach. The other study is suggested by changes that have occurred in the program itself. As noted, the single-point-of-entry function of program case managers has been expanded to include allied children's services. The research identified this as potentially affecting continuity of care; it deserves systematic investigation.

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Appendix A

Managing Continuity of Care for Children With Special Needs in Rural and Remote Northern Ontario

Interviews — Consent to Participate — Workers/volunteers

If you agree to give researchers permission for an interview, please read, sign and date the following consent form:

The purpose of this study is to determine which of two alternate approaches, the “mediator” model or the “intervention worker” model, provides greater continuity in managing the care of children with special needs in rural and remote communities.

The researchers ask that you assist in this study by consenting to an interview, which will last approximately 45 minutes. To ensure confidentiality, the interview will be held in your office or another place of your own choosing. There is no apparent harm to you in taking part in this study; it will not affect your employment or access to services. Care providers’ views will not be identified with parents and your employment will not be adversely affected by any criticism that you may make as a care provider.

To assist in documenting the interviews, we also ask that you give consent to audio taping of the interview. This will be done with the understanding that all field notes and tapes will be secured in locked cabinets in the Centre for Rural and Northern Health Research office, for a period of seven years after completion of the study, after which time it will be destroyed. Your answers will be confidential and you will not be identified in any written reports or subsequent presentation of results.

Your participation in the research is voluntary and you may decide to withdraw from the study at any time. Following the end of the project, you can request a written summary of the results from the researchers. A copy of the report also will be posted on the CRaNHR website.

I, _____, agree to be interviewed as part of the Centre for Rural and Northern Health Research/Centre of Excellence for Children and Adolescents with Special Needs study entitled “Managing Continuity of Care for Children with Special Needs in Rural and Remote Parts of Northern Ontario”.

In addition, please check one of the following:

_____ I give permission to the researchers to audiotape the interview.

_____ I do not give permission to the researchers to audiotape the interview.

Signature _____ Date _____

Managing Continuity of Care for Children
With Special Needs in Rural and Remote Northern Ontario

Consent to Participate — Children 12 Years of Age or Older

We are asking you to be in a research study. This form will tell you all about the study and help you to decide if you want to be in the study or not. Read this paper carefully and ask any questions you want. When we have answered all of your questions, you can decide to be or not to be in the study. This is called “informed consent.”

1. The purpose of this study is to determine what type of worker provides better care for children with special needs in rural and remote communities.
2. We ask you to help in this study by giving permission for your parents/guardians to be interviewed and asked questions about your care. There is no apparent harm to you or your parents in taking part in this study; it will not affect the care that you receive.
3. We will not tell anyone else about you taking part in the study and will not put your name on it. We will keep all information about the study in a locked cabinet at the Centre for Rural and Northern Health Research for seven years and then it will be destroyed.
4. We will use the information from this study to better understand the care that children like you receive. You will never be identified by name. Following the end of the study, you can ask for a written paper telling you what we found out.
5. You are a volunteer, which means you have the right to choose whether you want to be in this study. If you want to be in this study, you can sign this paper. If you don't want to be in the study, don't sign the paper. Being in the study is up to you and you can change your mind later if you don't want to be part of the study.

I, _____, give permission for my parents/guardians to be interviewed as part of the Centre for Rural and Northern Health Research/Centre of Excellence for Children and Adolescents with Special Needs study entitled “Managing Continuity of Care for Children with Special Needs in Rural and Remote Parts of Northern Ontario”.

Signature of Participant

Date

I have explained the study and this consent form to the participant and believe that she/he has understood it.

Signature of Researcher

Date

Managing Continuity of Care for Children
With Special Needs in Rural and Remote Northern Ontario

Interviews — Consent to Participate — Parents

If you agree to give researchers permission for an interview, please read, sign and date the following consent form:

The purpose of this study is to determine which of two alternate approaches, the “mediator” model or the “intervention worker” model, provides greater continuity in managing the care of children with special needs in rural and remote communities.

The researchers ask that you assist in this study by consenting to an interview, which will last approximately 45 minutes. To ensure confidentiality, the interview will be held in your home or another neutral place of your choosing. There is no apparent harm to you in taking part in this study; it will not affect you or your child’s access to services. Parents’ views will not be identified with workers and care of your child will not be adversely affected by any criticism that you may make as a parents.

To assist in documenting the interviews, we also ask that you give consent to audio taping of the interview. This will be done with the understanding that all field notes and tapes will be secured in locked cabinets in the Centre for Rural and Northern Health Research, for a period of seven years after completion of the study, after which time it will be destroyed. Your answers will be confidential and you will not be identified in any written reports or subsequent presentation of results.

Your participation in the research is voluntary and you may decide to withdraw from the study at any time. Following the end of the project, you can request a written summary of the results from the researchers. A copy of the report also will be posted on the CRaNHR website.

I, _____, agree to be interviewed as part of the Centre for Rural and Northern Health Research/Centre of Excellence for Children and Adolescents with Special Needs study entitled “Managing Continuity of Care for Children with Special Needs in Rural and Remote Parts of Northern Ontario”.

In addition, please check one of the following:

_____ I give permission to the researchers to audiotape the interview.

_____ I do not give permission to the researchers to audiotape the interview.

Signature _____ Date _____

Appendix B

Managing Continuity of Care for Children With Special Needs in Rural and Remote Northern Ontario

Interview Guide — Parents (Page 1 of 2)

We are doing research on the continuity of care provided through ISNC partnerships with local service providers for home and school programming and/or through ISNC's local intervention programs. We are interviewing parents or guardians chosen at random from two groups: (1) those whose children received intervention programming directly through ISNC therapists and local intervention workers, or (2) those whose children received home and/or school programming from ISNC therapists and hands-on intervention from either the parents themselves or others in the community.

We realize your child may have received services both ways. However, your name was included in the sample because they got (interviewer inserts either 1 or 2). Please answer the following questions with reference to those services specifically.

- Could you tell us what services ISNC has provided to your child
- Were you involved in decision-making?
- Were you involved in setting goals and developing the treatment plan?
- Were you involved in carrying out the treatment plan? Was the involvement helpful to you?
- Were you kept informed about your child's progress with the treatment plan? Was there regular contact with ISNC?
- Did you receive handouts and resource materials? Did they help you?
- Were local counselors and Case Managers able to arrange timely and comprehensive access to the specialists that your child required?
- Are you aware of local service providers using ISNC therapy assessments or therapist consultations to assist in their work with your child?
- Does the geographical location of your town affect ISNC's capacity to offer responsive services at times of need?
- If so, what does ISNC do to overcome the problem?
- Were you told who to call if a problem arose?
- If an appointment was cancelled or rescheduled, how were you notified about the change?
- If you needed to cancel or reschedule, were staff accessible and accommodating?
- Have the categories of ISNC care providers changed?
Have the individual care providers changed?
- If yes, how have the changes affected your child's motivation to achieve the goals that have been set?
- Have other categories of workers changed?
(Please specify, using the list below for reference).
 - education assistants
 - special education teachers
 - early intervention and prevention workers
 - child development workers
 - mental health workers
 - case managers
 - teachers

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Interview Guide — Parents (Page 2 of 2)

- Are there barriers to accessing diagnostic services, specialists and other recommended services?
- Was there continuous communication with the specialists? Was this sufficient?
- Have you ever received services from more than one ISNC worker at the same time? If so, how were the services coordinated?
- If your child was taken out of class to work with the intervention worker, did this concern you?
- Did referrals to other agencies/organizations assist you in understanding more about your child's diagnosis and treatment?
- Did the discharge plan provide you with opportunities to access further consultation, if required?
- Were you involved in conferences which involved both the school and ISNC personnel? Are such conferences beneficial for you?

- *Any further comments about continuity of care.*

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Interview Guide — Care Providers (Page 1 of 2)

We are doing research on the continuity of care provided through partnerships among ISNC and local services for children with special needs. We are looking at programs provided by ISNC intervention workers (SLP, Behaviour and OT/PT). As well we are interested in programming recommended by ISNC therapists and delivered by local service providers and caregivers working with children at home, at school or in other settings.

What is your relationship to ISNC?

In responding to the following questions, perhaps it will help to think about a particular child who has received ISNC services. However, feel free to draw on any experiences you have had with such cases.

- How was the treatment plan developed? Were components identified through ISNC consultation reports?
- Who was involved in implementing the treatment plan? Who kept it going?
- Did the plan rely on a therapist?
- Were meetings scheduled? With whom? Did they help?
- Were plans of care reviewed and revised in a timely manner?
- Were other needs identified?
- Were you aware of the goals in the plan of care and were they achieved?
- In general, do parents or guardians follow through with their children's plan of care?
- How does parental involvement affect their children's adherence to the plan?
- What strategies are used to determine what will encourage adherence to the program and plan of care?
- Does the timing of consultations influence the degree of adherence to the plan?
- In general, how satisfied are parents/caregivers with the frequency and regularity of contact?
- In your view, are parents/guardians satisfied with the degree of access they have to ISNC services?
- How helpful are ISNC therapist assessments in your work with a child seen by ISNC and continuing to be seen by you?
- Do you feel that the program, as currently structured, allows staff the flexibility to reschedule appointments to accommodate client needs?

- In general, are cancellations or changes sufficient to disrupt services?
- In general, how often do the individuals implementing aspects of a plan of care remain the same over the term of the care?
- If changes occur, to what extent are they due to: (a) staff turnover; (b) client's request; or (c) care provider's request?
- What strategies are employed to manage transitions in caregivers?
- How do changes in providers affect client's adherence to the plan of care?
- How useful are the materials provided by ISNC staff in helping parents/guardians to adhere to the plan of care?

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Interview Guide — Care Providers (Page 2 of 2)

- What efforts does ISNC make to advise parents/guardians about accessing required services after discharge?
- When clients receive a range of services, from ISNC as well as other organizations, to what extent are these services co-ordinated (e.g. between psychiatrists, psychologists and family physicians when pharmacological intervention is required)? Do you have concerns about this issue?
- Do clients have prompt access to diagnostic services recommended by ISNC?
- Are ISNCs local case managers able to co-ordinate access to specialist services (e.g. psychologists) in a timely manner?
- In your opinion, how frequently should case conferences occur? Do current practices fit with your expectations?
- In cases where clients choose not to access resources available in the district, what strategies does ISNC use to facilitate continuity in their care?
- What is done to support parents/guardians in their efforts to meet their children's special needs?
- To what extent are parents/guardians required to initiate consultations with:
(a) ISNC staff; (b) other professionals; and (c) school staff?
- In cases where parenting occurs in more than one household (e.g. as a result of divorce), what additional co-ordination is required to ensure both parents/guardians are involved in implementing the plan of care? Are the time and resources available sufficient to accommodate this need?
- *Any further comments about continuity of care.*