

L'allocation de services par catégorie et les entraves aux soins destinés aux enfants souffrant de maladies chroniques

Lynne D. Ray

Les parents qui élèvent des enfants atteints de maladies chroniques font face au défi de trouver et de coordonner les ressources et les services communautaires appropriés pour leur enfant. Cette analyse secondaire avait pour objectif de déterminer l'opinion des parents sur les mécanismes de prestation des services de santé et d'éducation et des services sociaux aux enfants atteints de maladies et d'incapacité chroniques, ainsi qu'aux familles qui s'occupent d'eux. Une analyse thématique a été effectuée à partir des données d'entrevues réalisées auprès de 30 mères et de 13 pères. Les parents ont décrit 11 mécanismes qui étaient utilisés pour déterminer l'admissibilité aux services ou le rationnement de ces derniers : le diagnostic, l'âge, la dépendance à la technologie, la gravité du problème, la capacité fonctionnelle, le statut de tutelle, l'emplacement géographique, les ressources financières, la capacité d'adaptation estimée des parents, le défaut d'informer les parents des services offerts, ainsi que la cyclicité du financement. Il s'agissait de mécanismes complexes, erratiques et sujets au changement. Des mécanismes intégrés, participatifs, souples et justes sont nécessaires afin de réduire la charge de travail des parents et d'assurer une prestation plus équitable des services.

Mots clés : soins pédiatriques à domicile, critères d'admissibilité, maladie pédiatrique chronique, incapacité pédiatrique, enfants ayant des besoins de santé spéciaux, aide familiale, politique en matière de santé, services de santé destinés aux enfants, accessibilité des services de santé

Categorical Service Allocation and Barriers to Care for Children With Chronic Conditions

Lynne D. Ray

Parents raising children with chronic conditions face the challenge of locating and coordinating appropriate community-based resources and services for their child. The purpose of this secondary analysis was to determine parents' view of the mechanisms used to allocate health, education, and social services to children with chronic illness and disability and their caregiving families. A thematic analysis was conducted on data from interviews with 30 mothers and 13 fathers. These parents described 11 mechanisms that were used to determine eligibility and/or to ration services: diagnosis, age, technology dependence, severity, functional ability, guardianship status, geographic location, financial resources, judged parental coping, failure to inform parents about available services, and cyclical funding. These mechanisms were complex, inconsistent, and subject to change. Mechanisms that are integrated, proactive, flexible, and fair are needed to reduce parents' workload and to ensure more equitable allocation of services.

Keywords: pediatric home care, eligibility criteria, pediatric chronic illness, pediatric disability, children with special health-care needs (CSHCN), family caregiving, noncategorical, continuity of care, health policy, child health services, health-services accessibility

Introduction

Parents who are raising children with chronic conditions face numerous challenges related to their child's care and the consequences of care for the family. Children with chronic illness and disability often require special arrangements and skilled care in order to remain clinically stable and capable of participating in typical childhood activities. These children may need specialized developmental programs, medical equipment, and communication and mobility aids. Their parents may require in-home support or respite in order to keep up with caregiving demands. To support a child and his or her family in the community, appropriate programs, services, and funding must be located and coordinated (Atkin & Ahmad, 2000; Hall, 1996; Jerrett & Costello, 1996; Ray, 2002; Rodriguez & Jones, 1996). Matching the child's or family's needs with available programs is no simple task. With the exception of acute inpatient episodes, ongoing care and developmental support for this

population takes place in the community, where the *Canada Health Act's* principle of universality does not apply. Policies that govern access to community-based services may be developed at a provincial, regional, or municipal level, and the funding may come from a combination of ministerial, private-insurance, philanthropic, and fee-for-service mechanisms.

When a child is first diagnosed with a chronic condition the parents assume that their primary-care provider will refer them to the services they need. Over time parents may find that their child does not meet the eligibility criteria for these referred services. Parents gradually realize that it is they who have ultimate responsibility for locating and coordinating community services. Professionals may not have authority across the range of services that a child requires and may not be aware of all the family's needs (Perrin, Lewkowicz, & Young, 2000).

This paper presents a secondary analysis of data from a study conducted to validate a model of the work required in raising a child with a chronic condition (Ray, 2002). In that model, "working the systems" refers to the work that caregiving parents do in locating services, funding, and equipment; arranging appointments; completing paperwork; and relaying information to various professionals. Parents in that study claimed that working the systems was the most frustrating aspect of raising a child with a chronic condition. An important finding of that study was the degree to which eligibility criteria served as barriers to care and sources of frustration for parents. A secondary analysis was conducted to examine these issues in greater detail. Its purpose was to determine parents' view of the mechanisms used to allocate health, education, and social services to children with chronic illness or disability and their caregiving families.

Methods

Recruitment and Sample

Participants were recruited through five agencies serving children in the community. The agencies were purposively selected to gain access to a broad range of clinical conditions, as is congruent with the noncategorical approach to sampling from populations of children with chronic conditions (Perrin et al., 1993; Pless & Perrin, 1985; Stein, Bauman, Westbrook, Coupey, & Ireys, 1993; Stein & Jessop, 1982; Stein & Silver, 1999). Children with exclusively developmental or behavioural conditions were excluded. Clinicians at the five agencies contacted families and sought permission to release their names to the investigator. The sample included English-speaking parents (30 mothers and 13 fathers) from 30 families in which at least one child had a chronic health condition

(34 children in total). The children ranged in age from 15 months to 16 years and the complexity of their care needs ranged from mobility aids to 24-hour ventilator support. Eighteen children had communication problems; nine used some sign language. Ten children had cognitive delays, which ranged from mild to severe. Another four children, believed to have normal intelligence, had severe motor disabilities that affected their communicative ability. Twenty children had mobility difficulties, ranging from impaired balance to total wheelchair dependency. Twenty-four children had a condition or treatment that was visible in some way. Enteral feeding was the most common form of technical care ($n = 11$), followed by mobility aids ($n = 8$) and oxygen and suctioning ($n = 5$). All of the children required multiple forms of care.

Data Collection

All but two of the interviews were conducted in the family home. Each family was interviewed once. When both parents participated, they were interviewed together. Parents were given a pie-chart model depicting topics related to their child's care and the consequences of the child's care for the family. The pie chart contained seven equal-sized sections labelled as follows: doing special care, parenting plus, working the systems, changing relationships, keeping yourself going, keeping the household going, and changing family priorities. *Special care* comprised the medical care, treatments, and symptom monitoring that the child required at home. *Parenting plus* referred to typical parental tasks such as supporting development, but because of the child's chronic condition persisted for a long period and with unusual intensity. *Working the systems* referred to coordinating care with health, education, and social-service professionals. *Changing relationships* included shifts within the nuclear family, extended family, and friends. *Keeping yourself going* referred to parents' efforts to cope with the emotional and physical demands of their situation. *Keeping the household going* included efforts to balance the needs of the ill child with those of the rest of the family. *Changing family priorities* referred to sacrificing some family activities and goals to accommodate the child's needs. These topics were explained both verbally and in the pie chart. The parents were thus prompted to elaborate on the meaning of each topic for their family. The interviews, which were audiotaped, lasted from 1 to 3.5 hours.

Data Management and Analysis

The interviews were transcribed verbatim and imported into Folio-Views™ (Ray, 1997) for data management. In the original study, the data were coded according to the seven segments of the pie chart. This served as a means of partitioning the 1,300 pages of transcript into manageable

sections. The current analysis was conducted on the segments initially coded under the broad category “working the systems.” These data contained all segments in which parents discussed their working relationship with the health, education, and social-service sectors and therefore reliably captured all data on service-allocation mechanisms.

A thematic analysis (Kvale, 1996; Tesch, 1988) was used to identify issues related to service allocation reported by parents. All data on eligibility, refusal of services, unsuccessful referrals, change in programmatic policies, and parental efforts to locate services or funding were coded as a separate subset. These data were then analyzed to identify all forms of eligibility criteria or mechanisms for rationing services that parents described either directly or indirectly.

Findings

Parents described a total of 11 different types of eligibility criteria or rationing mechanisms related to children’s services. These were diagnosis, age, technology dependence, severity, functional ability, guardianship status, geographic location, financial resources, judged parental coping, failure to inform parents about available services, and cyclical funding.

Diagnosis

The fundamental prerequisite for services was a specific medical diagnosis. Children who did not have a clear or common diagnosis were at a serious disadvantage:

The best thing is for that person to have a labelled problem, because if you have a labelled problem — those are the people who are best off. You get more help because people know about it. They’ve got groups that handle this. They’ve got clinics that handle it. But [not] if you have a case like [our son], and there’s lots like him, who don’t have a “syndrome” or something.

When diagnoses were clear and specific, both parents and professionals gained a sense of legitimacy, confidence, and predictability. In contrast, parents of children with unclear, uncommon, or multiple diagnoses were frequently told that their child fell into a “grey zone.” For example, a child who was unable to speak but could hear was not eligible for programs that taught sign language. Similarly, a child who was unable to speak but could hear and write and had normal motor skills was not eligible for speech computers. While the fundamental issue was communication, allocation of resources was based on hearing capacity alone.

Diagnosis not only served as a means of inclusion and exclusion, but it marked the boundaries of professional knowledge and scope of

treatment. For example, one child who was deaf-blind had been cared for in a program for multi-handicapped children. Her mother arranged for her to switch to a deaf-blind program, with the following results:

When people started approaching her as deaf-blind, anything she did was wonderful; she just started coming out of herself. We now had a kid who was out of herself, and not turned totally in. It was a phenomenal experience.

Professionals interpreted symptoms and priorities from the perspective of their clinical specialty, and if the fit was not appropriate the child's care could be suboptimal.

At a more abstract level of diagnostic categorization, children could be grouped according to whether their diagnosis was predominantly medical or predominantly neuro-developmental or behavioural. When families had one child with a medical condition and another child with a neuro-developmental condition they were able to compare service availability. They found that there were far more services for the child with a medical condition. One child with behavioural problems had no services while his medically ill brother had so many professionals following him that his mother was asking professionals to leave his case. This pattern of more services for medical conditions was observed across families as well. A mother made the following comment about her son who had both medical and behavioural problems:

I've always found the medical things a lot easier to deal with than the behaviour. With the medical, you feel like you can actually do something about it. Whereas this behaviour is, like, are you ever going to be able to get a handle on it?

Age

The age of the child often played a role in eligibility. Early-development programs seek to capitalize on the developmental window from birth to age 3 and many services stopped at that age. Other services were linked to the typical age of school entry or the transition to adult care. These typical developmental markers did not always correspond with the service needs of the children with chronic conditions. Parents of older children noted that the number of programs decreased as the child grew older. Another problem occurred when parents found out about services too late. One couple was told that they would have been eligible for respite had they applied when their child was younger.

Age became a troublesome issue as the gap between a child's chronological age and his or her developmental age became more noticeable. Debates about age-appropriate school placement were particularly challenging for parents, and solutions often depended on flexible programming within the school system:

I think that's what we need to look at: "Is what we're doing with this child giving him a chance to succeed? Or are we going to hinder him? Are we going to send him on the road to failure by pushing him ahead because of his chronological age?" So there are a lot of things that need to be considered. I think that's where we can change a bit and learn to be a bit more flexible.

Technology Dependence

Treatments that required technological support usually had funding priority over the more invisible behavioural management and personal care. Several parents mentioned that it was a piece of technological equipment that determined whether or not their child would receive certain services. One of the first systems for technology-based assessment was that developed by the Office of Technology Assessment (1987) in the United States and many programs have developed similar ones. While technology dependence provides an easy and tangible means of classification, technology-based classification can have unforeseen consequences for families:

It totally changes when your special-needs child goes into school. There's level 1, 2, and 3. [My daughter is] a level 3. She's the only child in the district that has an RN, which I am very thankful for because I have a choice in the RN. If your child is a level 2 and has a TA [teaching aide], parents don't have a say in anything and the child is basically bid on. That's how [the unionized system] works.

In this system, parents of children with less technological care experienced a turnover of teaching aides and some tried various strategies to make their child a more appealing choice for staff.

Severity

Severity is specific to the disease process and was implicit in most discussions of eligibility. Parents often assumed that severity was a prime consideration when professionals made in-home assessments to determine eligibility. However, parents were unable to articulate how judgements about relative severity were made. They did provide examples of severely ill or disabled children receiving less assistance than children who were not severely affected:

It seems like once you are on the program you are always on the program. Or they have these people who are on the program who they can't get off. ...I know of other kids who went on the program a few years ago that didn't have nearly the needs that [my son] has, but they got onto it then.

This inequitable access was seen as profoundly unfair. Since there is no universal system for assessing severity across diagnoses, and since severity judgement is a function of one's range of experience with children's conditions, it is unlikely that any global notion of severity will be perceived as fair.

Functional Ability

Categorization by functional ability was based on the child's ability to do age-appropriate tasks of daily living and was a common allocation mechanism. However, this type of categorization rarely reflected the complexity of the child's abilities:

I phoned the fellow in [the government office] and I said, "What would you like me to say?" I said, "I really need this." And he goes, "Well, your child can dress herself." Regardless of whether she puts it on backwards it doesn't matter. As long as she can pull those pants up, because they're elastic — and she still wears elastic to this day because she can't do buttons. Or she can pick up that spoon. It doesn't matter that you have to cut it into the tiniest pieces possible. But she can pick up that spoon and sort of put it in her mouth. These were their criteria. And I said, "Well, that may be fine for you to say, but you have no idea of what it took to get her there!"

Parents found that such screening mechanisms failed to consider the time it took to complete personal-care tasks or the quality and functionality of the result. Yet these qualitative nuances of the child's functioning were what determined the parents' caregiving workload.

Guardianship Status

While biological parents believed that foster parents had enviable access to services, foster parents were quick to note that fostering status was not always advantageous. Couples with both a biological child and a foster child with special needs were able to compare the relative benefits. One couple had sought funding for special equipment:

Then you have to go back to Social Services and say, "Hey, I need this." And they say, "Well, we've got nothing in the budget; go somewhere else." And then you've got somebody trying to get community funding, and they say, "No, you are under Social Services so they should be paying." So the Elks Club won't cover. So we were batting that ball for a long time.

This family's experience showed that a diagnostic label suggesting eligibility for one service can be detrimental regarding eligibility for other services.

Geographic Location

For several families, availability of services was the deciding factor in their choice of where to live. This had consequences for cost of living, the dwelling size they could afford, and options for career advancement. Once families had secured services in their area and had set up a program of care for their child, there was “no way” they were going to move and start the process again. Geographic immobility became a serious consequence of service categorization. The distribution of services also differed markedly by geographic location:

You are very limited as to where you can move to. For example, [City A] has very little money for children in the schools with special needs. The neurological centre does not serve them, so they have no resources within their city for special physiotherapy and all that stuff. So even within the [region] you have to be very careful where you move. [City B] is really good. [City C] is good. [City D] [is] not so great. But [City A]! You do not want to live in [City A] if you've got special needs.

Financial Resources

Needs testing, based on assessment of family income, is a longstanding mechanism for determining eligibility for services. Needs testing can be a degrading experience for parents. In recent years, employment-based or extended health benefits have come to play a greater role in families' ability to piece together services for their child. Families used a combination of funds from public-sector programs, employment-based benefit programs, and personal funds. One couple's son required 24-hour alert caregiving:

We actually use 1 day of [public home care] and then we use private hours on the Monday and the Wednesday morning, just through my husband's insurance. And then every other week we have some flex time from [public home care] and we use that to give us 6 nights of sleep.

This couple had very good coverage; in other provincial jurisdictions there is no public funding for night-time respite.

Judged Parental Coping

Parents believed that judgements about how they were coping played an important role in professionals' decisions about allocation of services such as respite. They told numerous stories of being expected to hold on as long as possible before receiving respite. “I think they're *told* to stall as many people as possible because they have budget constraints.” A common pattern was that those perceived to be coping received nothing.

The result was that parents, mothers in particular, were in crisis before they received help. They felt that recovering was a lengthy process and that a more preventative approach to respite would have avoided the cycle of burnout and recuperation. However, other parents tried to hold out and did not want to accept help. Some parents believed they were being perversely punished for successful coping, while others felt a sense of failure when they were deemed in need of respite.

Failure to Inform Parents About Available Services

All caregiving parents provided accounts of not being told about services or programs that might have benefited their child or family. Most attributed the lack of information to overworked staff, lack of knowledge among staff, poor coordination, or a lack of continuity of care. Others had become cynical and believed that professionals purposely withheld information from families to save “the system” money. Parents learned to be vigilant in seeking information about programs and in watching for policy changes in existing programs. One mother said, “We always have to be on our toes a hundred percent, or you get nothing; or you, or you’re child, is left to fall in the cracks.” When parents lacked the personal resources to invest in this search, they believed their children received inferior care.

Cyclical Funding

Some parents found that the key to accessing services was to apply before the annual budget ran out. This style of budget allocation usually applied to one-time expenditures such as for power wheelchairs or computer-assisted learning devices. Some parents knew which month a certain program usually ran out of funds. Other programs required regular retesting to ensure that the child was still eligible for services. Parents were quick to point out the lack of logic and waste of resources associated with this policy. For example, the parents of a girl who was clearly going to be wheelchair-dependent for life needed to get an annual letter of support from the pediatrician in order to maintain their handicapped-parking status. These routine eligibility checks appeared arbitrary and illogical to parents. As some parents asked: why would they want the trouble and stigma of special care if their child did not require it?

Interpretation

In the literature on parenting and chronic childhood conditions, the issues of eligibility criteria and mechanisms for allocating services to families are occasionally mentioned contextually. For example, Gillman, Heyman, and Swain (2000) note that a diagnosis can bring legitimacy

and access to services, while Hoyle (1992) demonstrates that a diagnosis can both facilitate and restrict access to services. Hall (1996) mentions the role of age in eligibility determination. Mahon (2001) notes that some parents find needs testing to be a degrading experience. The Federal Task Force on Disability Issues (1996) and McKellin (1995) illustrate clearly the geographic restrictions associated with access to services. Other studies report that there is a threshold at which parents' inability to cope precipitates intervention and the allocation of resources to the family (Blackman, 1998; Dowling & Dolan, 2001). While these issues are referred to in the literature, they have not been the subject of discussion nor has their collective impact been analyzed. This secondary analysis represents a shift in focus whereby service-allocation mechanisms and their consequences for families are addressed collectively.

Categorization, Rationing, and Fragmentation

While generally not acknowledged as such, categorization is a mechanism by which government ministries or departments, regional health authorities, and institutions allocate finite resources (Albrecht, 2001; Brown, 1995; Mechanic, 1995). Rationing determines both access to services and the quantity of services provided (Bourgeault et al., 2001). The mechanisms for categorization and rationing have profound consequences for families. The current mechanisms for categorizing children and families result in inequitable distribution of services. The participants provided numerous examples of categorical resource allocation based on categories and mechanisms that were incongruent with actual need.

Inequitable distribution or mismatch between need and allocation was a fundamental concern for parents. Some families had no services, others obtained help only after considerable lobbying efforts, some obtained help with relative ease, and others were embarrassed by the amount of help they had been offered. Often, once a child was in a program, eligibility determination for other programs became easier. Arbitrary eligibility criteria create the structural boundaries that result in parents' spending considerable time seeking appropriate services for their child. This situation was variously labelled "the black hole syndrome," "falling through the cracks," or being the "football" bounced between ministries — the common issue being that fixed structural boundaries lead to an abdication of responsibility on the part of government.

The structural and fiscal boundaries between the ministries of health, education, and social services have been causing difficulties for decades (Alexander & Henningsen, 2002). They represent the multiplicity of decisions made under a host of different organizational, social, and political circumstances (Brown, 1995). Categorization and allocation policies are set under different political parties, lobbying pressure,

managerial agendas, financial climates, and funding conditions. While each individual decision may have been reasonable in itself, frequently the cumulative result has no apparent logic, especially from the point of view of parents. The public tends to view tax dollars as one public purse, whereas professionals and administrators are accountable for one small portion and the budgetary system rewards the offloading of expenses to other ministries.

The net result of these structural weaknesses is a great deal of work for parents. Finding information, learning how the systems function, and staying current with policy changes is an extraordinarily time-consuming and frustrating process for a parent. Meanwhile, the health professional is put in the uncomfortable position of acting as service provider, advocate, and gatekeeper all at once (Bourgeault et al., 2001). This situation requires considerable tact and diplomacy on the part of both parties in the relationship between client and professional or administrator. Often, the marked power differential and conflicting roles create tensions among administrators, professionals, and parents.

Categorical Allocation and the Research Lens

The categorical distribution of services based on medical diagnosis is virtually unacknowledged in studies with children who have chronic conditions. This is partly a consequence of research design and sampling technique. The participants in the present study were recruited exclusively from community-based agencies, all but one of which served children with any combination of chronic illnesses or physical disabilities. The majority of studies of childhood chronicity, in contrast, recruit from diagnostic-based hospital programs or clinics. This recruitment strategy allows access to a large homogeneous population with minimal effort. For example, diabetes and cystic fibrosis are among the more frequently studied diagnoses (see, e.g., Grey & Sullivan-Bolyai, 1999; Hodgkinson & Lester, 2002; Johnson, Ravert, & Everton, 2001; Schilling, Grey, & Knaf, 2002). These are conditions for which there are specific treatment programs, and pediatric centres usually have multidisciplinary teams that work specifically with the families. While these families face extraordinary difficulties, they are not confronted with the diagnostic barriers to service access that were reported by the families in the present study.

A perennial debate in the chronic illness and disability literature centres around the issue of “lumping or splitting” (Mulvany, 2000; Perrin, 1999). When services for children and families are studied together (lumping), nuances in service needs can be missed. When they are studied by diagnostic group (splitting), those with uncommon diagnoses, multiple diagnoses, or unclear diagnoses are not represented in the research. In the

United States, a lack of comprehensive epidemiological data has led to inadequate funding for services. To address this problem several groups (Davidoff, 2004; McPherson et al., 1998; Newacheck et al., 1998; Stein, Silver, & Bauman, 2001) are attempting to define and identify the total population of children with special health-care needs. This epidemiological example, along with the illustrated ability to identify service barriers in the present study, demonstrates the consequences of studying the population through different research lenses and using different sampling approaches.

Improving Service Allocation

Given the current scarcity model under which resource-allocation decisions are made, some form of categorization and rationing of services is inevitable (Blackman, 1998; Perrin, 1999). However, mechanisms that are integrated, proactive, flexible, and fair are possible.

Integration. The need for better integration of services is clear. Both parents and care providers need to be able to plan a program of care without involving numerous programs and ministries. Various mechanisms have been tried to ensure that money follows the child and family rather than being split between ministries. For example, “block funding” links funds to the child, while other mechanisms allow funds to be shared by ministries. The participants in the present study wished to see truly comprehensive population-based programs that cross ministries. Integration efforts must overcome the funding and jurisdictional disincentives that perpetuate fragmentation (Perrin, 1999). Regardless of approach used, greater integration is a prerequisite to the provision of effective services to families.

Proactivity. Proactive service provision addresses two problems. The current needs-based allocation of services emphasizes deficits in the family’s ability to manage on its own. It also reflects a reactive approach. For example, respite should be viewed as preventative. Parents should not be left to reach “rock bottom” before receiving help and should not be made to feel that they have failed. A proactive stance has been adopted by some programs but is by no means universal. Similarly, parents will face new challenges at predictable transition points: school entry, the child’s reaching a weight where he or she can no longer be lifted by the parents, transition to adult services. Helping parents to plan for these transitions will save them from having to launch a new search for services at each stage.

Flexibility. The participants gave many examples of existing structures failing to meet the needs of their child and their having to make the child fit. This failing is reflected in all of the eligibility criteria.

Professionals and parents must be given the authority to put together a program of care that matches the child's needs and to allocate funds in a way that suits the family. For example, parents may prefer to have funding for a homemaker, instead of a caregiver for their ill child, so they can spend time with the child. Sensitive judgements about complex family circumstances can be provided only by skilled, knowledgeable professionals who have the authority to make individualized decisions (Blackman, 1998).

Fairness. The mismatch between the need for services and the availability of funding has generated much debate. While the parents in this study used the term "fairness," policy analysts discuss "equity" or the consistency and proportionality with which service-allocation decisions are made (Blackman, 1998). Both parents and policy analysts stress the need for greater transparency and accountability (Blackman; Light & Hughes, 2001). Parents need full access to information on programs, eligibility criteria, and decision-making processes. Cut-off points for eligibility criteria are constructed through fiscal, social, and political processes (Light & Hughes); rarely are eligibility criteria based on evidence that the categorical allocation is effective (Perrin, 1999). Evidence of fair and equitable allocation should be tested for both those who receive services and those who are excluded (Blackman).

The growing mix of public, private, and publicly funded contractual services provides additional complexity and the potential for inequitable allocation. For example, the role played by the child's illness severity, functional status, or technological dependence will vary according to the funding mechanism used. Social values provide public systems with incentives to target those with the greatest severity, while private, for-profit funding mechanisms provide incentives to target those who are "easy to serve." When funding and service-allocation decisions are driven by market forces rather than social policy, addressing the imbalances through advocacy becomes crucial (Pedlar & Hutchison, 2000).

The participants came to realize that, as parents of a child with a chronic condition, they had to develop advocacy skills. They frequently expressed concern for parents who had fewer personal resources or less developed advocacy skills; they believed that the children of these parents were at a disadvantage. Alternatively, caregiving parents may find advocates within the system, employees who are willing to take up the cause of a family, seek real solutions, or bend the rules on behalf of the family. Those participants who had access to insider advocates felt profoundly fortunate. Together these were the inequities that divided families and children into winners and losers. What the parents wished for was a level playing field.

Conclusion

This analysis examined the eligibility barriers that parents face when piecing together a community-based program of care for a child with a chronic illness or disability. The findings illustrate the complexity of the case-management responsibilities that parents assume and some of the factors underlying the inequitable allocation of services. Four principles are offered to guide policy development and the organization of services: integration of all levels of service and policy, provision of proactive planning for children and their families, flexible service planning tailored to each family's unique circumstances, and fair allocation of resources. In addition, both professionals and families need ready access to current information with regard to local services. Parents gave the clear message that they wished to invest their caregiving time and energy in their child rather than in navigating the complexities of the health, education, and social-service sectors.

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Comments or queries may be directed to Lynne D. Ray, Faculty of Nursing, 3rd Floor, CSB, University of Alberta, Edmonton, Alberta T6G 2G3 Canada. Telephone: 780-492-7558. Fax: 780-492-1926. E-mail: Lynne.Ray@ualberta.ca

Lynne D. Ray, RN, PhD, is Associate Professor, Faculty of Nursing, University of Alberta, Edmonton, Canada.