Journal on Developmental Disabilities
Le journal sur les handicaps du développement

OADD 20th Anniversary Issue

Spring 2006

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> *To foster and promote thoughtful and critical dialogue about relevant issues in the field of developmental disabilities, including those broader social issues that impact on persons with developmental disabilities.*

Content

Each issue features a selection of research, conceptual, informational, and editorial papers. An issue may have a central theme. Reviews of relevant books, movies, websites, software, and other resources are welcomed, as are letters to the editor. In this way we strive to collectively enrich our understanding of issues, encourage stimulating debate among those working in the field, and improve services.

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Submissions are invited in either French or English and, if accepted, will be printed in the language of submission with an abstract in the other language. Submissions must be free of any gender and ethnic bias. People-first language (e.g., persons with developmental disabilities) must be used throughout the manuscript (including figures and tables).

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Celebrating 20 Years of OADD

Selected Contributions From the Journal on Developmental Disabilities

Maurice Feldman and Adrienne Perry

When the OADD Board asked us to select key articles from previously published issues of the Journal on Developmental Disabilities (JoDD) to create a special issue to commemorate OADD's 20th anniversary, we knew we would be faced with a daunting task. In its relatively brief 12-year history, JoDD has published some outstanding articles and we knew we would have a difficult time choosing the final selection. Indeed, we found many more worthy articles than space permitted us to include.

The Journal's mandate is "to foster and promote thoughtful and critical dialogue about relevant issues in the field of developmental disabilities, including those broader social issues that impact on persons with developmental disabilities." While highlighting Canadian research, the Journal also strives to be pertinent to international research and issues.

In making our selections for this anniversary issue, we took the Journal's aims to heart. We chose articles of high quality and impact that addressed important areas in the field of developmental disabilities, from Canadian and international perspectives. We wanted our selection to reflect the diversity of research methods, issues, disciplines, theoretical approaches, etiologies and age ranges that have appeared in the Journal. The papers include literature reviews, conceptual papers, qualitative research methods, various quantiative research methods, including single-case and group designs, cross-sectional and propspective longitudinal designs. We also wanted to include Canadian and non-Canadian authors, and recognize those authors who have made multiple contributions. We feel that our final selection reflects a diversity of themes and provenance. Note that we did not include articles from the most recent issues because these are readily available on the OADD website.

We now will briefly introduce you to each article that we selected. We have presented them in chronological order. The first article is *Developmental Disability With and Without Psychiatric Involvement: Prevalence Estimates for Ontario* (1993), by Dickie Yu and Leslie Atkinson. Using Census information, the authors revealed that the Ontario government was "grossly" underestimating the Ontario prevalence of dual diagnosis (developmental disabilities coupled with psychiatric problems). The new estimates provided by Yu and Atkinson suggested that needed services for persons with dual diagnosis were woefully miscalculated and underfunded. In subsequent years, we have seen increased government recognition and support of services for these individuals, although much still needs to be done.

The next article, *An Acculturation Perspective on Deinstitutionalization and Service Delivery* (1994), by Katherine Buell and Patricia Minnes, presents a distinctly Canadian acculturation perspective to inclusion of persons with developmental disabilities. Buell and Minnes cogently argue that an acculturation model predicts four, not two, possible outcomes of community living for persons with developmental disabilities. They then applied this model to the existing literature on community inclusion and showed that previous reviews of outcomes may have been erroneous. Minnes and Buell have subsequently published several other articles in international journals, promoting and validating this model and a standardized measure of community outcomes.

In a paper entitled, *From Charity and Exclusion to Emerging Independence: An Introduction to the History of Disabilities* (1995), Gary Woodill and Dominique Velche provided an interesting review of the history of attitudes towards people with disabilities, including developmental disabilities. Although some of the terminology used in the past is now offensive to us, it is interesting to realize that the past is neither all bad nor all good but contains many of the same ideas and tensions as operate in the field today. Throughout history, society has been ambivalent, moving back and forth between two major orientations: on the one hand making provision for protecting, helping, treating, and educating people with disabilites; on the other hand excluding, controlling, and segregating people. Finally, as the title implies, Woodhill and Velche pointed out a few threads (historically and currently) of a third orientation, one of independence and self-determination.

In *The Effectiveness of a Three Session Consultation for Caregivers of Children and Adults With Developmental Disabilities* (1997), Joel Hundert tackled a perennial service issue faced by community behavioural services - long waiting lists. In a well-designed study, he demonstrated the short- and long-term effectiveness of a brief consultation model as an alternative to more typical intensive interventions. Many community behavioural services in Ontario subsequently have adopted similar models to triage and reduce their waiting lists.

In one of the few longitudinal studies of parents' decisions regarding placement of their children with autism, *A Prospective Study of Out-Of-Home Placement in Families of Children with Autism* (1997), Adrienne Perry and Anne Black identified key factors influencing parents' heart-wrenching decision to place their children with autism out-of-the-home. The authors addressed the research and service implications of their findings, and their study raised important questions of the relevance of services meant to support families in keeping a difficult child at home.

One of the top Quality of Life researchers, Robert Schalock, has published several articles in JoDD. In *The Conceptualization and Measurement of Quality of Life: Current Status and Future Considerations* (1997), Dr. Schalock tackled the thorny issue of how to conceptualize and measure Quality of Life in persons with developmental disabilities. His comprehensive formulation and precedent research directions, presented in this article, have guided much research and measurement in Quality of Life.

We also chose to include Maurice Feldman's Editorial, *Cost-benefit of Effective Interventions* (1998) which argued strongly for evidence-based and cost-effective services to be funded and made available and tied these principles to provincial policy papers recently-issued at that time. In particular, he focused on Intensive Behavioural Intervention (IBI) for young children with autism and Dual Diagnosis services for adults with developmental disabilities and psychiatric disorders. Considering this Editorial was written 8 years ago, it is somewhat surprising and heartening to step back and see how much has been accomplished in that time. Ontario is now the world's largest single-source provider of IBI programs with nine regional centres, and more specialized programs are being funded for persons with dual diagnosis. At the same time, we would all agree much remains to be done.

James Bebko and colleagues present a scholarly review paper entitled *Social Competence and Peer Relations in Children with Mental Retardation: Models of the Development of Peer Relations* (1998) which is solidly grounded in the developmental psychology literature on early parent-infant relationships, peer relationships, and friendships in typically developing children and adolescents. The authors examined what was known about these issues in children and youth with developmental disabilities and the implications of having poor social competence on psychological adjustment. They reviewed what (surprisingly little) was known about intervention strategies to enhance social competence and made recommendations for future research.

The paper by Tricia Vause and colleagues entitled, *Training Task Assignments and Aberrant Behaviour of Persons With Developmental Disabilities* (2000) was selected from a Special Issue devoted to an assessment procedure known as the *Assessment of Basic Learning Abilities* (ABLA). We chose this particular ABLA paper because it dealt with several issues of relevance to the field, especially for those supporting more severely affected adults, including the clinical utility of designing suitable day program activities which are well-matched to individuals' specific abilities, staff training to improve this match between individuals and tasks or activities, and prevention of problematic behaviour by customizing the individuals' environment to suit their ability level.

An Investigation into the Characteristics of the Maltreatment of Children with Developmental Delays and the Alleged Perpetrators of this Maltreatment (2002) by Ann Fudge Schormans and Ivan Brown was an important study dealing with a very difficult reality. Children with developmental disabilities are at greater risk for abuse and neglect than other children. This study examined a large child welfare database and investigated the types of child maltreatment (neglect, emotional, physical, sexual) and characteristics of the maltreatment (frequency, duration, whether the perpretrator was a family member or stranger, socio-demographic characteristics of perpetrators, and so on). Complex interactions of socioeconomic factors and supports and services for families need to be further investigated and there are clear implications not only for child protection, but also for providing supportive services to families caring for children with developmental disabilities.

Continuing on the theme of research about and with families, we have included Shabana Kausar, Ronna Jevne and Dick Sobsey's paper, *Hope in Families of Children With Developmental Disabilities* (2003). This is a report of a qualitative study of parents describing their experiences parenting a child with a disabilty. There were eight themes which emerged and an overarching theme linking them all together which was that of "hope" (presented visually as being the hub of a wheel). This paper is important because it speaks, in parents' own words, of the positive and growth-oriented aspects of their lives, rather than focusing solely on their stress and difficulties.

Another example of the cutting-edge research presented in JoDD, is seen in *Human Rights and Persons with Intellectual Disabilities: An Action-Research Approach for Community-Based Organizational Self-Evaluation* (2003), by Dorothy Griffiths and her colleagues. Although empowerment and self-determination are cornerstones of the community living movement, it appears that rights of persons with developmental disabilities still may be restricted. This article described one of the first attempts to systematically identify community rights restrictions of persons with developmental disabilities, from their own, and their support staff's, perspectives. The results of this survey were used to design systemic human rights training programs for persons with developmental disabilities, support staff and community living agencies.

We are honoured that OADD asked us to prepare this anniversary issue. We hope that you find that our selections do indeed capture the quality, breath and depth of the journal's first 12 years. We acknowledge OADD for its dedication to the dissemination of knowledge through its ongoing support of this Journal. We thank all the contributors to the Journal, as well as past and current Editors, Editorial Boards and reviewers for making the Journal on Developmental Disabilities the premiere research-focused developmental disabilities journal in Canada. We look forward to its continued growth and influence. Happy reading!

Developmental Disability With and Without Psychiatric Involvement: Prevalence Estimates for Ontario

Dickie Yu and Leslie Atkinson

Abstract

Epidemiological studies can be used to assist in service planning, budgeting and research. However, interpretation of prevalence estimates must be moderated by caveats. This paper highlights several issues and problems related to prevalence and provides estimates for people with developmental disabilities and people with both developmental and psychiatric involvement (the latter is often referred to as "dual diagnosis") in Ontario based on the 1991 census (Statistics Canada, 1992). Estimates have also been calculated for Toronto because it is the largest city in Ontario. Readers interested in other regions should be able to apply the prevalence rates to the city population of interest from Statistics Canada (1992). It is not the intent of this paper to provide a comprehensive review of epidemiological studies or to provide detailed analysis of prevalence by demographic and etiological variables.

Issues and Problems in Prevalence Estimates

Studies that use the International Classification of Disease (1980), 9th Revision (ICD-9), definition of mental retardation tend to yield slightly higher estimates at each level of retardation than the AAMD definition (Grossman, 1983) due to differences in IQ ranges (McLaren & Bryson, 1987). Also, studies that use the single IQ-below-70 criterion tend to yield higher estimates than the dual components criterion of IQ-below-70 and deficits in adaptive behaviours. However, proponents of the single IQ-below-70 criterion have argued that there is a lack of consensus on what constitutes "successful adjustment" and that the determination of adaptive behaviour deficits is heavily influenced by the intensity of detection efforts (e.g., Zigler & Hodapp, 1986).

Intensity of Detection Effort

Prevalence increases with increased intensity of detection effort. For example, data derived from total population screening yield higher estimates of people with developmental disabilities (approximately 2 to 2.5%) than data derived from multiple agencies and registers (approximately 1%). It has been suggested that the latter sampling technique tends to underestimate prevalence (McLaren & Bryson, 1987). Prevalence also increases with age, peaks during late school years (approximately 20 years old), and declines during post-school years. This has been attributed to (1) a lack of reliable assessment, except for the most severe cases, and a tendency to avoid labelling in preschool-age children; (2) increased demands and detection effort in school settings; and (3) decreased detection effort in post-school years and the tendency to avoid labelling. It has been argued that prevalence in fact remains stable throughout the life span and changes in prevalence reflect changes in detection effort (Granat & Granat, 1973). Detection is also complicated by the unavailability of standardized IQ assessment, especially for people with moderate and mild disabilities (due to the trend to avoid labelling and decertification) and a lack of standardized use of adaptive behaviour assessments (McLaren & Bryson, 1987; Zigler & Hodapp, 1986).

The 3% Versus 1% Controversy

According to Zigler and Hodapp (1986), the 3% prevalence is derived as follows. Starting with an IQ-below-70 criterion, approximately 2.28% (two standard deviations below the mean of 100) of the general population would be placed in the retarded range. Added to this are individuals with known organic etiologies, estimated to be approximately one-third of the developmentally disabled population without organic cause (2.28% + .76% = 3.04%).

Proponents of the 1% prevalence rate (e.g., Mercer, 1973; Tarjan, Wright, Eyman & Keeran, 1973) argue that the single IQ-below-70 criterion is inadequate; deficits in adaptive behaviours must also be considered. While 3% of the population may be considered to be developmentally delayed at birth (incidence), only 1% is identified as developmentally disabled at any given time as a result of successful social adaptation and a higher mortality rate of individuals with developmental disabilities.

Zigler and Hodapp (1986) suggested that 1% is too low and 3% is probably too high. Considering that longitudinal studies of intelligence show that IQ is relatively stable throughout the life span, that there is a lack of consensus on "successful social adaptation," that there is a lack of identification of preschool-age children, that the developmentally disabled population has a shorter life span in general, and that prevalence is heavily influenced by the intensity of detection effort, they argued that the prevalence of developmental disabilities is relatively stable across age groups. By adjusting for the lack of identification of children under 5 years old and for the shorter life span of individuals with developmental disabilities, they proposed that prevalence probably lies between 2 to 2.5% (Zigler & Hodapp, 1986).

Prevalence of People With Developmental Disabilities

McLaren and Bryson (1987) reviewed 21 epidemiological studies conducted in several countries (Denmark, England, Finland, Ireland, Japan, Netherlands, and Sweden) and Canadian Provinces (Maritime Provinces, Quebec, Ontario, Manitoba, and British Columbia). Virtually all studies relied on the ICD-9 definition of mental retardation, the single IQ-below-70 criterion, and data derived from multiple agencies and registers. Overall, prevalence of individuals with IQ below 50 (moderately, severely, and profoundly disabled combined) was approximately 3 to 4 per 1,000 and approximately 4 to 6 per 1,000 for individuals with mild disabilities, thus giving a total of close to 1% prevalence.

In contrast, Zigler and Hodapp (1986) reviewed 10 studies, conducted in England, Scotland, Sweden, and the United States, which examined the population at large and included strong attempts to identify previously unidentified cases. Prevalence ranged from 0.67 to 7.44%, with a median of 2.25%.

The prevalence of people with developmental disabilities in Ontario has been estimated to be 0.43% excluding institutionalized individuals (Lundy, 1983). Using this estimate and the 1991 population figures for Ontario (10,084,884) and Toronto (3,893,045) (Statistics Canada, 1992), approximately 43,000 individuals in Ontario and approximately 17,000 individuals in Toronto, respectively, would be developmentally disabled.

These figures are likely to be underestimates since the prevalence rate (0.43%) is well below the 1% found in studies which were thought to have underestimated prevalence (McLaren & Bryson, 1987), Moreover, the number of people with developmental disabilities living in the community has increased substantially as a result of deinstitutionalization over the last 10 years. If prevalence is assumed to be 1%, approximately 101,000 individuals in Ontario and approximately 39,000 individuals in Toronto, respectively, would fall within the range of developmental disabilities. If prevalence is assumed to be 2.25%, approximately 227,000 individuals in Ontario and 88,000 individuals in Toronto, respectively, would fall within the range of developmental disabilities. While we tend to concur with Zigler and Hodapp's (1986) proposition that prevalence of people with developmental disabilities is approximately 2.25%, this is hardly a consensus among epidemiologists.

Prevalence of People With Developmental Disabilities and Psychiatric Involvement

Epidemiologists studying the combined prevalence of developmental disability and psychiatric disturbance are faced with the problems of defining and identifying both the developmental and psychiatric components in their target population. This issue is not only intrinsically difficult, but each component of the diagnosis confounds the other. Thus, psychiatric disturbance often depresses intellectual functioning in an individual who would not otherwise be considered developmentally disabled. Likewise, developmental disability often overshadows psychiatric disturbance to the extent that the latter is ignored.

For these reasons, estimates of the percentage of developmentally disabled individuals who also suffer psychiatric involvement very greatly, anywhere from around 15% to 60% (median = 37.5%) (c.f., Craft, 1959; Dewan, 1948; Duncan, Penrose & Turnbull, 1936; Gollay, Freedman, Wyngaarden & Kurtz, 1978; Heaton-Ward, 1977; Iverson & Fox, 1989; Neuer, 1947; Pollock, 1945; Weaver, 1946). All investigators concur, however, that developmentally disabled individuals are more prone to psychiatric disturbance than are their non-delayed peers, whether this be attributed to biology (Berg & Gosse, 1990) or to psychosocial factors (Reiss, Levitan & McNally, 1982). In fact, the prevalence of psychopathology among developmentally disabled individuals may be four or five times that of the normally intelligent population (Matson, Kazdin & Senatore, 1984).

Within Ontario, it has been estimated conservatively that 6,800 adults may meet the diagnostic criteria of both developmental delay and psychiatric disturbance (based on the Ministry of Community and Social Services statistics for 1987). This figure represents "only those most seriously affected…With a less restrictive definition of dual diagnosis, the number of individuals would be much higher" (The Provincial Community Mental Health Committee, 1988).

Our review of the literature suggests that this figure is probably a gross underestimate. Assuming a 2.25% prevalence for people with developmental disabilities and the median estimate for dual diagnosis mentioned above (37.5%), then we would calculate that approximately 85,000 individuals in Ontario and 33,000 individuals in Toronto, respectively, experience simultaneous developmental and psychiatric involvement.

In summary, epidemiological studies with more vigorous detection methodologies tend to support a prevalence of 2.25% for people with developmental disabilities. The range of estimates for people with both developmental and psychiatric involvement appear to be much broader. As assessment and diagnosis techniques continue to improve, such as for preschool-age children and for people with psychiatric disorders, future epidemiological studies with strong detection methods will add precision to the present estimates. The determination of prevalence rate is not a mere theoretical or scientific exercise; it has practical consequences for resource allocation and service planning. Prevalence information on demographic variables and etiological factors may also be useful in guiding the focus of future research.

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An Acculturation Perspective on Deinstitutionalization and Service Delivery

M. Katherine Buell and Patricia M. Minnes

Abstract

Deinstitutionalization efforts are reinterpreted through an acculturation framework. This framework defines four relationship options among smaller and larger groups within a culture. Assimilation, Integration, Segregation, or Marginalization is defined by two issues: the extent to which cultural relationship is maintained, and the value attributed to the distinctiveness of an identified group. The framework is adapted to the field of developmental disabilities. These four options provide relevant definitions for the outcome of deinstitutionalization efforts when persons with developmental disabilities are the identified group. The adapted framework was successfully applied to the community outcome literature, used to clarify normalization and service delivery intent, and overcomes a methodological research error in the outcome literature.

Over the years of deinstitutionalization, authors have identified the need for a larger theoretical framework regarding service delivery (Bruininks, 1990; Bachrach, 1985). The application of normalization principles (Wolfensberger, 1972) or social role valorization principles (Wolfensberger, 1983) to deinstitutional service delivery has proved to be challenging. For purposes of discussion in this paper, the more familiar term normalization will be used, as social role valorization is not a new concept but rather a change in terminology (Wolfensberger, 1983). The discrepancy between normalization in theory and normalization in practice has often precipitated controversy (Chappell, 1992; Elks, 1994; Landesman & Butterfield, 1987). However, as Bruininks (1990) accurately noted, "Without the application of philosophical concepts both to organization of services…research and practice would be unduly limited" (p.14).

The initial appeal of normalization, focussed as it was against institutions, becomes vaguer in its contemporary implementation among community alternatives (Mesibov, 1990). The contemporary issue becomes one of applying the normalization philosophy to the community alternatives deinstitutionalization has created. Therefore, given the continuing lack of empirical direction for implementation in even more complex situations, it has become important to provide a theoretical perspective that incorporates normalization and allows it to direct service delivery efforts. One solution to this problem is to provide an overriding theoretical framework to clarify the philosophical concepts of normalization and to facilitate their implementation in practice.

An Acculturation Framework

The following acculturation framework is offered as an "application of philosophical concepts" to help understand the process of service delivery for persons with developmental disabilities. This proposed framework, borrowed from cross cultural psychology, provides an interpretation of normalization principles and assists in defining implementation goals.

Table 1: Options in the Acculturation Framework

		Issue ONE: Is it considered valuable for the smaller cultural group to maintain cultural identity and characteristics?	
		yes	no
Issue TWO: Is it considered valuable for the smaller cultural group to maintain relationships with other groups, or the larger cultural group?	yes	Integration	Assimilation
	no	Segregation/ Separation	Marginalization

The framework, developed by Berry (1984) for the study of culture contact and acculturation, concisely describes the various ways in which smaller groups can interact within the larger dominant culture. Table 1 illustrates the acculturation framework (Berry 1993, personal communication; Buell, 1994).

In general, one of four acculturation relationships is determined on the basis of affirmative or negative resolutions to two hypothetical issues. These issues relate first, to the importance or value of maintaining the distinctiveness of the smaller group apart from the larger dominant group (Issue ONE: Is it considered valuable for the smaller culture group to maintain cultural identity and characteristics?), and second, to what extent positive relations are sought or valued by the smaller group with the larger group (Issue TWO: Is it considered valuable for the smaller cultural group to maintain relationships with other groups?). The two-by-two matrix resulting from the resolution of these two issues determines integration, assimilation, segregation, and marginalization. These four options reflect the manner in which the smaller and larger groups interact or have cultural contact. Integrations results when both the issues are resolved affirmatively–the smaller group wishes to maintain cultural identity and characteristics while maintaining positive relations with the dominant culture. Assimilation results when the resolution to Issue ONE in no (cultural identity is not valued and maintained); the smaller group minimizes distinctiveness and shares positive relations with the dominant group. In effect, integration and assimilation are defined by an affirmative answer for positive relations with the culture at large.

In contrast, when relations are not maintained with the culture at large, the resolution defines segregation or separation, and marginalization. Segregation or separation is defined when the answer to Issue ONE is yes, while the answer to Issue TWO is no; the smaller group wishes to maintain its cultural identity and characteristics (its distinctiveness) independent of relations with the larger group. The degree of power held by the smaller group to determine the nature of this relationship with the larger group distinguishes separation (i.e., the group has the power to determine) or segregation (i.e., the group does not have the power to determine). Marginalization results when the resolution to both issues is negative. The smaller group's distinctiveness (cultural identity) is not valued or retained and therefore confused while maintaining relations with the dominant culture are not valued or sought and are therefore ambiguous.

Framework Applied to Persons With Developmental Disabilities

The original framework as described by Berry has been used to describe the interactions among and between various cultural groups within a society (Berry, 1993; Berry, Kim, Power, Young & Bujaki, 1989). In simplifying the framework, two useful perspectives are those of either the larger culture or the smaller group. Depending on perspective, the issues resolve to explain how discrepancies and conflict can arise within a culture. The major purpose of this paper is to clarify issues around deinstitutionalization by defining persons with developmental disabilities as the smaller cultural group within the larger group of society and by defining normalization as the cultural relationship which is maintained.

Several authors have found it useful to describe persons with developmental disabilities as a subculture or smaller group (Bercovici, 1981, 1983; Landesman-Dwyer & Berkson, 1984; Rhoades & Browning, 1982). The original framework can be revised to incorporate the perspective of developmental disabilities and will be referred to as the adapted acculturation framework (Table 2). The adapted acculturation framework redefines the issue of valuing and retaining cultural identity and characteristics. Issue ONE asks whether the uniqueness of this population is recognized. "Is it considered to be of value to maintaining cultural identity and characteristics?" becomes defined as an issue of "whether the unique characteristics of persons with developmental disabilities are recognized and supported." Assuming that relations with the culture are maintained (an affirmative answer to Issue TWO), the upper matrix becomes relevant. Normalization, as a philosophy, minimizes differences or de-emphasizes unique characteristics, and it follows that assimilation is the service delivery outcome for persons with developmental disabilities. Alternatively, the recognition of unique characteristics results in another option, an integration option, where service delivery outcomes stress the need for supports for these characteristics and for maintaining relations with the larger community.

Table 2: Options In The Adapted Acculturation Framework

		Issue ONE: Is it considered to be of value to recognize and support the unique characteristics of persons with developmental disabilities?	
		yes	no
Issue TWO: Is it considered of value for persons with developmental disabilities to maintain relationships with other groups?	yes	Integration	Assimilation
	no	Segregation	Marginalization

Normalization controversies consist of differing views of the unique characteristics of individuals with developmental disabilities (normalization is assimilation, an alternative is integration.) But in the adapted acculturation framework, the terms are more clearly defined and separated, and 'assimilation' and 'integration' are not to be used interchangeably as they frequently are in the literature. In Berry's framework, these terms refer to two distinct situations. The controversy resolves itself if the emphasis shifts from similarity with the culture (assimilation) to valuing differences (integration) while emphasizing on-going contact with the culture.

In adapting the acculturation framework Issue TWO is retained. Issue TWO, "Is it considered to be of value to maintain relationship with the larger society?" becomes restates as "Is it considered of value for persons with developmental disabilities to maintain relationships with other groups?" In reference to the framework, the lower half of the matrix becomes relevant. A negative resolution to this issue of maintaining relationships will result in segregation/separation or marginalization. These options are independent of how the smaller group, the persons with developmental disabilities, view their unique characteristics. For purposes of this discussion, maintaining relationship with the larger culture is defined as a service delivery issue determined by public policy (legislation) and will be further elaborated in the following section.

Service Delivery as a Cultural Relationship

For purposes of adapting the original framework, Issue TWO, maintaining relationship with the culture, defines service delivery. At the same time, service delivery is also defined by normalization. Here the aim of service delivery is to develop "behaviours and characteristics as culturally normative as possible" (Wolfensberger, 1972, p. 28) ultimately indistinguishable from the general public, that is, a service delivery that transforms people from visible to invisible (Rhoades & Browning, 1982). The adapted acculturation framework shows that service delivery based on normalization principles is a resolution to Issue ONE that de-emphasizes the unique characteristics of persons with developmental disabilities. The answer is no to "whether the unique characteristics of persons with developmental disabilities are recognized and supported." This is what is explicitly stated in the definition of normalization.

The answer to Issue TWO is also found in the definition of normalization. "Utilization of means as culturally normative as possible" (Wolfensberger, 1972, p. 28) assumes an affirmative answer to Issue TWO. The answer is yes to "Is it considered of value for persons with developmental disabilities to maintain relationships with other groups?" Therefore, service delivery outcomes include positive relationships with the culture. The expected outcome for deinstitutionalization is a positive answer to Issue TWO.

Referring to the matrix in Table 2, service delivery based on normalization would define a successful outcome as assimilation. If the major focus of service delivery and deinstitutionalization is repatriation into the culture then outcome can be defined by Issue TWO. A successful outcome would be defined by yes to Issue TWO, thus providing two service delivery options, both integration and assimilation. It appears then that defining service delivery as a cultural relationship is a valid premise.

Application to the Deinstitutionalization Literature

This discussion has more than theoretical relevance. The adapted acculturation framework was operationalized and incorporated into a larger review of the deinstitutionalization literature. Databases representing the multidisciplinary nature of the field of developmental disabilities, respectively, education (Educational Resources Information Center (ERIC)), psychology (Psychological Abstracts (PsycLit)), and medicine (Medline) were searched using the key words "deinstitutionalization," "mental retardation services," "normalization," "integration," "mainstreaming," "community living," "group homes," "mentally handicapped," "mental retardation," "developmental handicap," and "mental retardation-rehabilitation."

A study was included as part of the review if it met two criteria: (1) the study was concerned with persons identified as "mentally retarded," "developmentally handicapped," "mentally defective" or any of the expressions used to define those of below normal intelligence; (2) the study was undertaken between the years 1972 (when normalization was formally introduced to North America) referenced prior to 1990, and involved discussion of changes in living arrangements from one alternative to another alternative. A third criterion was exclusionary–references which referred to specific legal actions that litigate someone versus someplace (or variants) were *not* included unless there was a concomitant study of the outcome of the move.

Each study was read and rated according to specific criteria established prior to reading the article. The validity of the assumptions for adapting the acculturation framework was tested. The options in the adapted acculturation framework were operationalized in terms of the assumptions, namely unique characteristics (special), and relationship with the community. These options were applied to the literature as part of a quantitative literature review. An inferred rating was based on the language use in the article describing the community living alternative. The inter-rater reliability using these categories was 84%. Table 3 illustrated the definitions and the percentage of studies that fell into each category (Buell & Minnes, 1994).

Table 3: Operationalized Framework Applied To The Outcome Literature

Integration 17.4 % - the alternative is identified as "special" – supports and services are provided through the community or generic services but may require specialist / facility supports - aggregation of retarded individuals is implied as necessary or important in certain cases / situations - the setting recognizes the need for supports (emphasizes differences) and has on-going positive relationships with the community	**Assimilation 2.1 %** - service and supports are provided through community and generic services - there is no aggregation of retarded individuals or identification as "special" - the setting emphasizes similarities with the general community and has on-going positive relationship with the community
Segregation 26 % - the alternative is identified as "special" – supports and service are provided through specialists and are directed at the needs of the occupants of the setting and there is little emphasis on the use of generic services - aggregation is the expected manner of service delivery - the setting emphasizes need for supports and has little relationship with the community	**Marginalization 0 %** - the alternative is vaguely identified - there is minimal mention of supports and services - the situation appears to be isolating, warehousing with little emphasis on individual needs - the setting emphasis is vague and has little relationship with the community
Unable to categorize 54% of the studies due to lack of descriptive information.	

Discussion

The results of this review application contradicted the expected service delivery outcome based on the normalization philosophy, that is, assimilation, minimizing unique characteristics and maintaining on-going contacts. Regarding the first assumption, minimizing unique characteristics, the majority of deinstitutional outcome studies (43.3%) were coded as integration and segregation options. This result suggests that the unique characteristics of persons with developmental disabilities were recognized by service delivery providers reported in the literature. This is in contrast to the ideological aims of normalization, as described through the adapted acculturation framework.

The second assumption regarding maintaining contacts with the dominant culture was also contradicted by the data. A majority (26%) of the discrete options within the framework were classified using the segregation option. This result was counter to the theoretical intent of service delivery and conflicts with normalization principles. In terms of Issue TWO, maintaining contact with the larger culture, the actual segregation effect of deinstitutionalization contrasted with the ideal assimilation goal.

Statistically, the expectations of minimized uniqueness and maintaining contact were not supported. Given that the deinstitutionalization of persons with developmental disabilities presumably had normalization principles as a theoretical base, it would be hypothesized that assimilation would have a greater percentage of alternative outcomes. However, the chi-square statistic was non-significant (χ^2=1.574,χ^2_{C}(.05)=3.84). These outcome data did not support the theoretical alternative.

Forty-six studies potentially provided information that could be rated using the adapted acculturation model. Fifty-four percent of the studies could not be classified. This indeterminate result is significant for two reasons. First, although the stated aim of the reviewed research was evaluation of deinstitutional outcome, 54% of these studies presented no information about community relationship or supporting unique characteristics. Second, this lack of information illustrates a methodological artifact within the deinstitutionalization outcome literature. While the studies claim to be evaluating service delivery outcome (deinstitutionalization), the research outcome focus generally is on individual outcome measures, predominantly related to adaptive behaviour (80%), and not on aspects of service delivery. Despite the shift in emphasis introduced by Wolfensberger, this is, from the individual to the services provided for that individual (Zigler & Hodapp, 1986), the studies continue to emphasize the converse and thereby perpetuate theoretical incongruence. The adapted acculturation framework presented here overcomes this artifact, the individual versus service delivery. The framework provides a theoretical perspective that defines service delivery outcome.

In summary, the acculturation framework defines the ideal normalization service delivery outcome as assimilation, that is, the unique characteristics of persons with developmental disabilities are de-emphasized, while maintaining ongoing cultural contacts. The acculturation framework, operationalized and applied to the outcome, illustrates the actual service delivery outcome as integration and segregation, that is, the unique characteristics of persons with developmental disabilities is not de-emphasized. The framework also provides a clarifying definition for service delivery outcome. This overcomes the methodological artifact currently limiting the literature on deinstitutionalization and is more in agreement with current trends in service delivery (A.A.M.R., 1992).

Conclusions

The acculturation framework was adapted to the field of developmental disabilities by basing it on three premises: persons with developmental disabilities are a smaller culture, they have unique characteristics, and cultural contact is defined by service delivery. The successful application of the adapted acculturation framework through the review of the literature provided support for these premises. The adapted acculturation framework defined the ideal normalization service delivery outcome as assimilation. The application of this framework to the deinstitutionalization literature provided an empirical definition of service delivery outcome. The results showed the outcomes of deinstitutionalization to be integration or segregation. Contrary to normalization principles (Wolfensberger, 1972, 1983), service delivery goals do not appear to include making people with developmental disabilities indistinguishable from the public, rather, their unique characteristics were acknowledged.

The adapted framework can provide a general definition for service delivery outcome. If deinstitutional outcome were defined in terms of the adapted acculturation framework, such a definition could then facilitate the definition of service delivery outcomes. Moreover, by focussing on outcome, the adapted framework potentially overcomes the failure of current prognostic variables (measures of intellect, personality, skills, or life circumstances) to predict community adjustment (Edgerton & Bercovici, 1976).

Finally, through the explicit definition of the terms assimilation and integration, the adapted acculturation framework could overcome the imprecise use of language prevalent in discussions about deinstitutionalization (Bachrach, 1985; Landesman-Dwyer, 1985).

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From Charity and Exclusion to Emerging Independence: An Introduction To The History Of Disabilities

Gary Woodill and Dominique Velche

Persons who are intellectually or physically different have traditionally been treated with ambivalence in Western societies. On the one hand, there is the “humanitarian” tradition, the impulse to help those perceived to be in need. On the other hand, there is the “social control” tradition, the tendency to want to hide or rid ourselves of those among us who don’t fit in.

These dual positions of assistance and repression towards persons with disabilities have a long history in our society, starting with the attitudes of the ancient Greeks, Romans, and Hebrews, and continuing through the history of Christianity. More recently, a third attitude – promoting independence – has gradually been building over the past thirty years. In this brief overview of the history of disabilities, we try to show how the balance between assistance and repression has shifted over time, and how it is now being replaced by a new attitude of supporting maximum independence for persons with disabilities.

From Antiquity To The Enlightenment

In ancient Greece, being born with a physical difference was seen as a sign of anger of the gods. The Greeks exposed such “marked” infants to die in order to appease the gods. At the same time, they provided pensions for soldiers who had become disabled as a result of wounds in battle (Stiker, 1982). The Romans abused persons with disabilities in circuses and other forms of entertainment while, at the same time, they developed medical procedures designed to cure or prevent certain disabilities (Scheerenberger, 1982). The Hebrews, as recorded in the Old Testament, held that a person with a disability is blemished and therefore unable to “offer the bread of his God” (Holy Bible), but also believed that persons in need were to be cared for by the community. Christianity has projected this dualism by associating disability with sin, while promoting healing and forgiveness of those who have sinned (Le Disert, 1987).

In the Middle Ages in Europe, those who were intellectually or physically different were often found living in the community, but at the same time, were usually living as poor beggars. Being a disabled beggar at that time was an advantage, in that it was easier to receive alms from the rich if disability were present. Organized guilds of disabled beggars existed, sometimes sharing their “take” and helping each other.

The Enlightenment brought new “scientific” ideas on how to diagnose, classify, and treat the “unwanted” of society. The 1500s in Europe was the period of the development of state welfare, the establishment of locked institutions for those seen as undesirable, and the beginning of medical involvement in the determination of who was really “disabled” (and therefore deserving of welfare), and who was not.

With the rise of science, human beings became both objects for study and for “treatment” by experts steeped in scientific culture. Thus, Francis Bacon’s ideas on the domination of nature through the new scientific method were a precursor to Itard’s experiments with the Wild Boy of Aveyron. Locke’s sensationalist theory of the primacy of experience in learning, promoted in France by the Abbé Condillac, provided the philosophical foundations of the new methods of teaching blind, deaf, and intellectually impaired children. Rousseau’s call for a return to nature led directly to the methods of “object teaching” found in the pedagogies developed by Pestalozzi, Froebel, Seguin, and Montessori. The French philosophes, such as Diderot, Voltaire, Rousseau, Condillac, and La Mettrie, questioned the legal, moral and religious foundations of the French state while, at the same time, believing in the idea of progress through science and reason. The ideas of progress, perfectability of humans, individual freedom, the efficacy of empiricism, the importance of direct experience and concrete activity to learning, and many aspects of modern Western culture were Enlightenment ideas on which the new methods of educating and treating disabled children were founded (Winzer, 1986).

The Rise of Special Education

Special education with children who were labelled at the time as “idiots” and “imbeciles,” began at the end of the 18th century in Zeitz, Germany, in an “industrial school” which offered additional tutoring for children who were “slow.” The school was open all days of the weeks except Sundays. Students learned to do work with flax, sew, and draw. Children who had insufficient knowledge for their age received one to two hours of additional help. The idea was that children were to be useful to industry, as well as to develop skills.

Early efforts at educating children with disabilities often were the initiative of private tutors. For example, in 1819, in Germany, Johann Vollharth was involved with “blind, deaf, and blind idiot” children whom he taught in his private school in Weimar. In 1820, another German, Johann Traugott Weise, a teacher at the school for the poor in Zeitz, wrote a book entitled *Observations about mentally weak children in regards to their diversity, basic sources of problems, characteristics, and the methods by which, in a gentle manner, through education, we can help them: With special reference to the Pestalozzian methods of calculation.* Weise also introduced the traditions of the industrial school into the school for the poor to help the students who were behind. His colleagues complained because he forced them to help the children who were behind, even at mealtime, without pay. He was one of the first educators to develop a systematic plan for special education, and he believed that teachers had to be trained to work with these children. When he died, however, there was no immediate follow-up to his efforts, and the extra tutoring of intellectually impaired children stopped.

Elsewhere in Germany, by 1834 there were also special tutoring classes within the school in Halle, but these ended after a few years. In 1835 a special school in Chemnitz for those who were “deranged” and “those in need of help” was instituted. A second special class was started in Chemnitz in 1856. By 1860 this special class in Chemnitz became a tutoring class where children in need received separate instruction for 13 hours, later 17 hours, per week. The view of special education at that time was that the special help could be ended after a period of time, and that the children in the special class would be returned to their regular classrooms.

In 1859, another special education class was started in Halle with 17 boys and girls who were “not mentally complete,” deaf, blind, physically weak, or “so badly neglected that they could hardly speak.” The Halle class became a separate institution in 1862 with a curriculum which consisted of Bible study, reading, writing, arithmetic, singing, and, for girls, hand work such as knitting and sewing. These various pioneering efforts in Germany were reviewed in a 1864 study by Heinrich Ernst Stötzner entitled “Schools for children who are not very capable.”

During the same period, Jean Itard in France began to work with “Victor,” the “wild boy of Aveyron.” Itard, who worked at the Deaf and Dumb Institute in Paris, first saw Victor in 1799. He and Madame Guerin tried to teach Victor to speak and to read. They were only partly successful, but their methods, along with those evolved by Itard’s successor, Edouard Seguin, started a tradition which drew attention to the importance of sense-training and stimulation in the development of children’s cognitive abilities. At the Salpetrière Hospital, Seguin used Itard’s methods to teach intellectually impaired children to read, write and draw, and invented various teaching devices to aid his students. (These were later adapted by Maria Montessori). In the United States, the teaching of "idiot children" began as early as 1818 at the American Asylum for the Deaf and Dumb in Hartford, Connecticut:

> *It is not to be understood, however, that idiots had not been instructed, in this country, previous to the Autumn of 1848, the period when the experimental school, at South Boston, was organized. Indeed, there is reason to believe that their instruction had been attempted, with success here, prior to the first efforts in Europe. As early as 1818, an idiot girl was admitted into the American Asylum for the Deaf and Dumb, at Hartford, Conn., and remained under instruction till 1824. Others were received during nearly every subsequent year, and some of them made very considerable progress. In all, thirty-four idiots have been pupils at that institution, and the success which has followed the efforts for the instruction of several of the cases, of which we have a detailed narrative, would do no discredit to any Asylum for Idiots, either in Europe or this country.* (Brockett, 1856)

In 1830 in France, Dr. Voisin published a report entitled "Application of the physiology of the brain to the study of children needing special education," one of the first uses of the term "special education." The next year J.-L. Falret created a school at the Salpetrière for 24 "idiots, imbeciles and chronic slow learners." In 1845, Seguin, tired of problems with the administration of the hospital, founded his own private school for such children on rue Pigalle in Paris.

Seguin's fame had spread throughout Europe and North America. Influenced by his methods, the first school for "idiots" in England opened in 1846, followed by the first such school in the United States in 1848. In 1848, Seguin emigrated to the United States where he helped set up educational programs for "mentally deficient" children in the newly formed "training schools."

At the same time as Seguin was developing his "physiological method" for educating children with developmental disabilities in France, Guggenbühl in German Switzerland, and Saegert in Berlin developed their own approaches to teaching children and adults in terms of sensory-motor training and socio-vocational goals. Guggenbühl opened one of the first specially built institutions for intellectually impaired persons near Berne, and this institution was visited by leaders in the field of "mental deficiency" from many countries, including Dr. Samuel Gridley Howe, founder of the first residential schools for blind children and “mentally defective” children in North America.

The migration of Seguin to the United States spurred on the development of educational institutions for persons with intellectual impairments, so that by 1876 there were twelve training schools in eight states. “All of these schools, frequently in the face of public opposition, were conceived primarily as training schools for education and release rather than as custodial asylums” (Doll, 1962). Seguin credited H. B. Wilbur with adapting his method to classroom instruction:

> *Wilbur laid great stress on motivation – in arousing the will and the senses from lethargy by utilizing in progressive sequence the muscular feelings, the appetites, the desire for movement, the gratification of the senses, curiosity, affection, and finally intellectual and moral discrimination. Habit was used to govern selfdetermination. He also emphasized the involvement of the child in active learning with concrete objects and a close relationship between observation, inference, and practical use. He especially interested himself in the developmental aspects of communication.* (Doll, 1967).

The Eugenics Movement

The optimism of the 1840s and 1850s gradually turned to pessimism in the late 19th century. The work of Itard, Seguin and Montessori was eclipsed by hereditarian Darwinism and the belief in the immutability of intelligence which characterized American psychology of the early twentieth century. Consequently, Seguin’s enlightened educational approach was replaced by the eugenics movement of the early twentieth century, which resulted in the institutionalization and forced sterilization of many persons with intellectual impairments in North America.

By the 1880s, intellectually impaired persons were no longer viewed as “unfortunates” or “innocents” who, with proper training, could fill a positive role in the home and/or community. As a group, they had once again become undesirable, frequently viewed as a great evil of humanity, and placed in the same category as the vagabonds, criminals, prostitutes, and paupers. Anyone remotely connected with the possibility of transmitting “mental deficiency” was viciously attacked. In 1891, the 51st Congress of the United States amended the Immigration Act to exclude “all idiots, insane persons, paupers or persons likely to become a public charge, persons suffering from a loathsome or a dangerous contagious disease, persons who have been convicted of a felony or other infamous crime or misdemeanour involving moral turpitude, polygamists...”

The eugenics movement in the United States received much support from several studies of the family backgrounds of selected intellectually impaired people. In an 1877 study, Richard Dugdale traced the lineage of the “Jukes” family through six generations (Dugdale, 1877), locating 709 out of 1200 descendants. Those related directly by blood to the Jukes had a preponderance of problems, while those related by marriage or cohabitation did not. Although Dugdale attributed the results to environmental factors, his study was interpreted by many as proof of the influence of heredity.

Goddard’s 1912 study of the lineage of the “Kallikak” family was also very influential for the hereditarians and those who advocated “negative eugenics” through sterilization or segregation. In Goddard’s book the photographs of presumably feebleminded rural kin of “Deborah Kallikak” were retouched with heavy lines which accentuate the facial features.

Like much of the Western world, Great Britain was to experience a “eugenics scare” at the beginning of the 20th century which would greatly influence the treatment of people with intellectual impairments (Barker, 1983; Macnicol, 1983; Ray, 1983; Woodhouse, 1982). For Henry Maudsley, a eugenics advocate, it was a question of national survival. The Report of the Interdepartmental Committee on Physical Deterioration (1904) tried to demonstrate that the British, who had just lost the Boer War, were in a poor physical state, thus contributing to the theory that the nation was in danger of immediate “degeneracy.” Degeneracy theory was first developed by Morel in France in the 1850s and essentially held that:

1. hereditary trait is polymorphous, that is, the degenerative tendency expresses itself in different ways and with different forms of deviance;
2. acquired traits are transmitted to the offspring, and thus parental experiences have an effect on offspring; and
3. the condition would become progressively worse from generation to generation if not checked. (Abbott & Sapsford, 1987)

The response to the eugenics movement in Great Britain was a call for segregation because sterilization of persons who were intellectually impaired was deemed to be to controversial.

Alfred Binet in France, who developed the first intelligence test, was an exception to the pessimism of the eugenics movement. He believed that intellectual levels could be improved over time through "mental orthopaedics," a series of exercises designed to improve the intelligence level of "slow" children. But Binet and Simon's work reached the United States in 1908 through Henry Goddard, an outspoken hereditarian who had been appointed director of research at the Training School for the Feebleminded in Vineland, New Jersey. Goddard, who advocated a unitary view of intelligence determined by heredity, was also an enthusiastic supporter of eugenics. By not allowing the "mentally defective" to procreate, he believed, the human stock would be improved. Although he privately supported compulsory sterilization, he felt that the public was more likely to accept his other proposal – collecting and segregating persons with intellectual impairments into closed institutions like Vineland.

However, misgivings about the wisdom of establishing segregated classes and schools existed from the beginning. The city authorities of Berlin in 1898 wrote, regarding the establishment of special schools, that "the definitive assignment of children to such a school would place upon them the stamp of inferiority for all time, and often prematurely" (Sarason & Doris, 1979). Instead, they preferred the use of auxiliary classes, "but always with the purpose of replacing the special instruction as soon as possible by the regular." An editorial in a leading newspaper in Canada in 1880 railed against special classes for "problem children," arguing, "The boys would be 'branded'! They would be shamed for life! And – most impossible of all – how could such characters be disciplined? The only hope would be the slender one of finding a man of exceptional skill and power in the management of bad-boy nature." Thus, resistance to exclusion also has a history, but one which is not well documented.

From Assistance and Repression to Independent Living

There is a third tradition in the history of disabilities which has received little attention. This is the tradition of "self-help" by and among persons with disabilities. In the Middle Ages, before the organization of human service professions, persons with disabilities formed guilds or other forms of association for mutual self-help. For example, in the 14th century in Spain, there were associations of blind persons at Barcelona and Valencia (Le Disert, 1987). Its bylaws, written in 1329, provided for the mutual loan of guides, visits to each other in case of sickness, and a fair division of alms received.

The modern "self-help" movement in the field of disability has its roots in the 1960s with the anti-psychiatry movement, the "living-in-community" model developed by Jean Vanier in the L'Arche communities in France and elsewhere, and the civil rights movement in the United States. These beginnings developed into various self-help movements for persons with disabilities, such as the Independent Living movement and People First. Because of the newness of these movements, detailed histories of them still need to be written.

The history of disabilities is, for the most part, a mix of examples of charity and exclusion. Only now are we seeing examples of resistance to these dominant attitudes in the form of arguments for inclusion and movements for independence.

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The Effectiveness of a Three-Session, Brief Behavioural Consultation for Caregivers of Children and Adults With Developmental Disabilities

Joel Hundert

This study examined the impact of a three session brief behavioural consultation on changes in consultees' (e.g., parents, teachers, group home staff) behaviour ratings of children and adults with developmental disabilities referred for behavioural services. Also of interest was the proportion of consultees who opted for no additional behavioural services after receiving brief behavioural consultation. Using a randomized, yoked-control group design, consultees were either placed in a waiting list control (WL) group or in a brief behavioural consultation (BBC) group. In the BBC group, consultees were helped to formulate an intervention plan, based on behavioural principles and consideration of contextual factors affecting program implementation. Changes in consultees' perception of the frequency and the stress of clients' presenting behaviour problems were evaluated for both groups, with the interval between pre- and post-assessment for consultees in the WL group, yoked to consultees in the BBC group. The results indicated a significant reduction in the perceived frequency of clients' behaviour problems and consultee stress experienced by those problems for both groups, with significantly greater reduction for consultees receiving the brief behavioural consultation. The perceived reduction of client behaviours continued 18 months after the intervention, with no difference between consultees receiving BBC and those on the waiting list who subsequently received a more extensive behavioural intervention. Moreover, approximately 63% of consultees in the BBC group wished no further services compared to 6% of consultees in the WL group.

Over the past two decades, there has been increased emphasis on providing services for individuals with developmental disabilities in such community settings as early childhood centres (Chandler, 1991), elementary schools (Salisbury & Vincent, 1990), secondary schools (Handen, Feldman, & Honigman, 1987), family homes (Feldman et al., 1986) and group homes (Maisto & Hughes, 1995). These community settings are faced with the challenge of accommodating the high rate of behaviour-emotional problems that often occurs with persons with developmental disabilities. The prevalence of behaviour-emotional problems in the population of persons with developmental disabilities has been estimated at five-times that of the non-disabled population (Borthwick-Duffy, 1994; Crews, Bonaventura, & Rowe, 1994; Koller, Richardson, Katz, & McLaren, 1982; Rutter, 1970). These adjustment difficulties are most often exhibited as aggression and social skills deficits (Reiss, 1990) that hamper life outcomes, including reduced opportunities for social integration and successful community placements (Bruininks, Hill, & Morreau, 1988).

The increasing placement of children and adults with developmental disabilities in community settings coupled with the high rate of behaviour problems, have increased waiting lists for behavioural services supporting individuals with developmental disabilities (Hayden, & DePaepe, 1994). One possibility for responding to the increased pressure for services is to search for briefer, yet effective, forms of treatment that may enable some clients to be supported successfully without resorting to the high service intensity usually associated with more extensive forms of behavioural intervention. A brief behavioural consultation may be provided as an alternative for some clients being placed on a waiting list. If effective, this brief intervention could result in service savings to be expediently used for client with less tractable behaviour disorders.

Behavioural consultation emphasizes working with the consultee on identifying and arranging environmental events affecting the client to reduce problem behaviours and to strengthen prosocial alternatives. Behavioural consultation has been successfully used in a variety of situations including, helping classroom teachers to increase students’ academic performance and social behaviours (Allen & Kramer, 1990; Fuchs, Fuchs, Bahr, Fernstrom, & Stecker, 1990; Lalli, Browder, Mace, & Brown, 1993); assisting a pediatric patient to cope with hospitalization for severe burns (Hurt & Tarnowski, 1990), and aiding families at home with children who are socially withdrawn (Sheridan, & Kratochwill, 1992). Recipients of consultation show greater gains than individuals not receiving consultation, but no one model of consultation (e.g., behavioural, mental health, organizational) has been shown superior to the others (Medway & Updyke, 1985).

Although behavioural consultation has been applied in a variety of settings and is found to be effective, it tends to be time-consuming to implement. For example, Fuchs et al. (1990) reported that teachers who received behavioural consultation from “mainstream assistance teams” complained of the length of the consultation. Even after a shorter version was developed, behaviour consultation took 14 to 22 days to complete. Although brief or time-limited therapies have been found to be about as effective as longer forms of psychotherapy (Crits-Christoph. 1992; Svartberg, & Stiles, 1991), there has been no evaluation of a brief form of behavioural consultation.

Brief behavioural consultation differs from more extensive versions not only on the time dimension, but also in its high reliance on a collaborative approach in which the consultees are involved in the development as well as the implementation of a behaviour program. Involving individuals in the design of interventions has been found to increase their commitment to the developed plan (York & Vandercook, 1990). A collaborative approach, entailing a coequal relationship between consultant and consultee has been rated by elementary teachers (Babcock & Pryzwansky, 1983) and early intervention professionals (Buysse, Schulte, Pierce, & Terry, 1994) as preferred to an “expert” model of consultation.

Aside from other savings, one of the advantages of brief behavioural consultation lies in its potential to reduce the waiting list for services. It is possible that a proportion of consultees receiving brief behavioural consultation will benefit to a sufficient extent not to require additional behavioral consultative services. These are cases that would otherwise be placed on the waiting list for services.

The purpose of the present study was to evaluate the relative effectiveness of a three-session, brief behavioural consultation on reducing the frequency of behaviour problems of children and adults with developmental disabilities, compared to a waiting list. Of particular interest was the impact of brief behavioural consultation on reducing consultees’ requests for additional behaviour interventions.

Method

Behavioural Service

The behaviour consultation service provided a range of community-based, behavioural-oriented services to developmentally disabled children and adults with behaviour-emotional problems who resided within an urban/rural catchment area surrounding a city of 400,000 people in southern Ontario. Referrals to the service could be initiated by families, physicians, group home operators, and educators, with consent of guardians of clients 12 years or younger or who lacked the "capacity" to give informed consent. Clients with "capacity" gave consent to the consultation.

Participants

Clients consisted of a total of 21 children and 20 adults with developmental disabilities referred to a behaviour consultation service, specifically established for this population. Each client was referred by a different consultee (e.g., parent, teacher, residential counsellor). A description of gender, age, diagnosis and presenting problem of the clients and the characteristics of the consultees initiating the referrals are shown in Table 1.

Table 1. Characteristics of clients and caregivers

	Brief Behavioural Consultation (n=21)		*Waiting List Control (n=20)*	
	n	*%*	*n*	*%*
Percentage of Male Clients	14	66.7	5	85.0
Client's Diagnosis				
Mild/moderate mental retardation	7	33.0	5	25.0
Developmental delay	3	14.3	3	15.0
Cerebral palsy and severe mental retardation	3	14.3	3	15.0
Pervasive developmental delay	2	9.5	1	5.0
Prader-Willi syndrome	2	9.5	1	5.0
Severe mental retardation	1	4.8	2	10.0
Epilepsy and severe mental retardation	1	4.8	2	10.0
Trisomy 14	0	0.0	1	5.0
Unknown	2	9.2	2	10.0
Client's Age				
0-10 yr	8	38.1	6	30.0
11-20 yr	3	14.3	4	20.0
21-30 yr	5	23.8	6	30.0
31-50 yr	4	19.0	3	15.0
>50 yr	1	4.8	1	5.0
Client's Presenting Problem				
Self-injury	4	19.0	3	15.0
Aggression	4	19.0	4	20.0
Self-care Deficits	2	9.5	1	5.0
Tantrums	2	14.3	1	5.0
Disruptive Behaviour	8	38.1	11	55.0

(continued)

Table 1. (cont'd)

Identity of Caregiver				
Parents	8	38.1	9	45.0
Teachers	2	9.5	0	0.0
Group Home Staff	11	52.3	11	55.0

Measures

Client behaviour. Two measures were used to assess changes in client behaviour after brief behavioural consultation. One measure was the AAMD Adaptive Behavior Scale: Residential and Community Edition (Part II) (ABS, Nihira, Foster, Shellhass, & Leland, 1975) administered with the adaptations described by MacDonald (1988). MacDonald (1988) found that compared to standard administration of the measure, higher rates of interrater reliability and item-by-item agreement occurred when consultees rated client behaviours using operational definitions. Consultees reported the number of times that clients displayed each of 39 behaviour categories (e.g., damages personal property, is withdrawn) during the previous week.

Consultee stress. The second measure evaluated the amount of stress consultees attributed to the clients' presenting behaviour problems. The perception of stress of an event has been identified as a critical factor in how well individuals adapt to a stressor (Hill, 1958) and in the referrals of boys with behaviour problems by their mothers to a mental health clinic (Griest, Forehand, Wells, & McMahon, 1980).

A 5-item *Perceived Behaviour Stress Scale* (PBSS), shown in the Appendix 1, was developed for this study, based on the *Perceived Stress Scale* (Cohen, Kamarck, & Mermelstein, 1983). Split-half internal reliability estimates of the PBBS produced an acceptable Cronbach's coefficient alpha of 0.81, although the small sample size should be noted.

Request for additional service. The impact of brief behavioural consultation also was evaluated at the point of post-assessment by asking consultees in the BBC group whether they wanted additional behavioural services provided by the clinic (e.g., parent group, more intensive behaviour consultation); the consultees in the WL group were asked whether they wanted to continue to wait for service. This information provided an estimate of the potential impact of brief behavioural consultation on reducing the waiting list for services.

Design

A 2 (brief behavioural consultation vs. waiting list control groups) by 3 (pre-, post-, vs. follow-up assessment) factorial design with repeated measures was used to evaluate changes in client behaviour after receiving brief behavioural consultation. Successive referrals by consultees to a behaviour consultation service were assigned at random to either a brief behavioural consultation (BBC) group (*n*=21) or a waiting list control (WL) group (*n*=20). Consultee rating of the frequency of client behaviour problems and the amount of stress caused by those problems were collected before and after brief behavioural consultation and 18 months later. Consultees in the WL group receive more extensive consultation in the interval between post- and follow-up assessments. To equate for the interval between pre and post-assessments, each consultee in the WL group was yoked to the subsequent consultee in the BBC group. The average interval between pre- and post-assessment was 7.2 weeks. Both measures were administered to consultees 18 months after post-assessment, at which point, the sizes of the two groups fell to 10 and 12 for the BBC and WL groups respectively, for the PBSS and 5 and 6 respectively, for the ABS. This large attrition rate at follow-up was due to the high mobility of consultees and clients and may have compromised the integrity of the follow-up results, rendering them only suggestive.

Brief Behavioural Consultation

Brief behavioural consultation consisted of approximately three sessions during which the consultees were led through steps to view behaviour problems within an ecological framework and develop a behavioural intervention using social learning principles (Coleman & Minnett, 1992). The steps were similar to those described by Fuchs, Fuchs, Bahr, Fernstrom, and Stecker (1990): (a) problem identification, (b) identification of possible contextual issues that contribute to the problem, (c) collaborative problem-solving, and (d) implementation and evaluation of the plan. During the initial session, the consultant explained that with the limited number of sessions, the consultant's role was to assist the consultee in the formulation of plan, based on the consultee's ideas. The consultant asked the consultee to describe: (a) the client's behaviour problems, (b) the client's competencies, (c) the consultee's opinion of the functions of the behaviour, (d) the interventions that had already been tried, and (e) the factors that had hampered past success. Based on this discussion, the consultant helped the consultee identify critical ingredients to a successful plan for the client's behaviours, drawing on behavioural and contextual principles (Dumas, 1989). The consultee was asked to develop a more specific intervention based on these critical ingredients for the subsequent session. The consultant prepared and mailed a written summary of the discussion and the decisions that occurred during the first session. Frequently used techniques were positive reinforcement, errorless learning, extinction, and task analysis (Alberto & Troutman, 1990; Bellack & Hersen, 1985).

During the second session, the consultee presented the plan to the consultant or if the consultee had not prepared a plan they worked together on the plan. The consultant provided positive feedback, but also identified programming obstacles and remaining programming issues.

The third session typically consisted of assisting the consultee in the implementation of the plan by either providing on-site feedback, or by discussing the consultee's report of implementation issues. It was left for the consultee to select the type of implementation support desired.

The brief behavioural consultation was provided by a total of four staff who had university degrees in psychology, training as behaviour consultants, and averaged 5.6 years of experience. On average consultees received 2.9 sessions of brief behavioural consultation, for a mean of 4.8 hours of service, over a mean interval of 6.5 weeks. Prior to the beginning of the study, consultants were trained in brief behavioural consultation by the author using modeling, coaching, and feedback until each was judged to have met the eight fidelity criteria of brief behavioural consultation shown in Table 2.

Treatment fidelity was evaluated by audio taping one-third of the sessions at random. A judge, naive to the purpose of the study, scored the audiotapes as to whether each of the criteria in Table 2 was met during the session. The mean rating of consultants' adherence to the intervention components was 96.8%.

Table 2. Fidelity criteria for the first session of brief behavioural consultation

- The consultant indicated that the role of the brief behavioural consultation was to facilitate the consultee's development of a plan, based on examination of the behaviour problem.
- The consultant lead a discussion of the topography, frequency and functions of the behaviour problem.
- The consultant lead a discussion to identify contextual factors that would affect consultee implementation of an intervention.

(continued)

Table 2. (cont'd)

- The consultant provided feedback on the consultee's strengths and used these to assist in the development of a plan.
- The consultant identified key ingredients for the consultee to consider in developing an intervention plan and invited discussion.
- The consultant asked the consultee to develop a more detailed plan for the following sessions.
- The consultant wrote a summary of the plan of action and mailed it to the consultee within 3 days.

Results

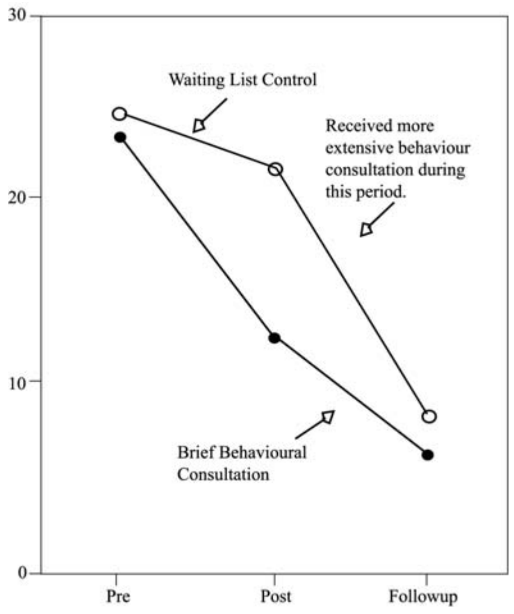
Pre-Post Differences

There were no significant differences between the BBC and WL groups on their pre-assessment results for the ABS or the PBSS. Pre-post changes on the measures were calculated by a 2 (groups) by 2 (pre- vs. post-assessment) repeated measures Analysis of Variance (ANOVA). A separate ANOVA was computed for each of the two measures rather than using a Multivariate Analysis of Variance, because each measure was viewed as representing separate dimensions rather than connected linearly. Calculation of product-moment correlation between the PBSS and ABS total scores in this sample (r=.05), suggested that there was little relationship between consultees' rating of the frequency of clients' behaviour problems and the stress attributed to those problems.

The mean pre- and post-assessment scores on the ABS for each of the two groups are shown in Figure 1. It can be seen that there was a significant decrease in consultees' ratings of the frequency of clients' behaviours for both experimental groups, $F(1,37)=27.8$, $p<.001$, with a significant interaction between time and groups, $F(1,37)=8.44$, $p<.001$, indicating that consultees receiving the brief behavioural consultation showed more reduction in their rating of the occurrence of client behaviour than those waiting for service. Changes in consultee ratings of clients between pre- and post-assessment were reanalyzed to determine the percentage of consultees rating client behaviour as better (a gain of greater than .5 standard deviations), worse (a decline of greater than .5 standard deviations) or the same (a change no greater than ± .5 standard deviations). Twice as many consultees in the BBC group as the WL group rated their client as better

(80.1% vs. 44.4%), $\chi^2(2)= 6.02$, $p<.05$. Similarly, about twice as many consultees in the WL group as the BBC group rated their clients as worse (16.7% vs. 9.5%).

Figure 1. Mean scores on the Adaptive Behavior Scales for the Brief Behavioural Consultation and the Waiting List Control groups at pre-,post-, and follow-up assessment.



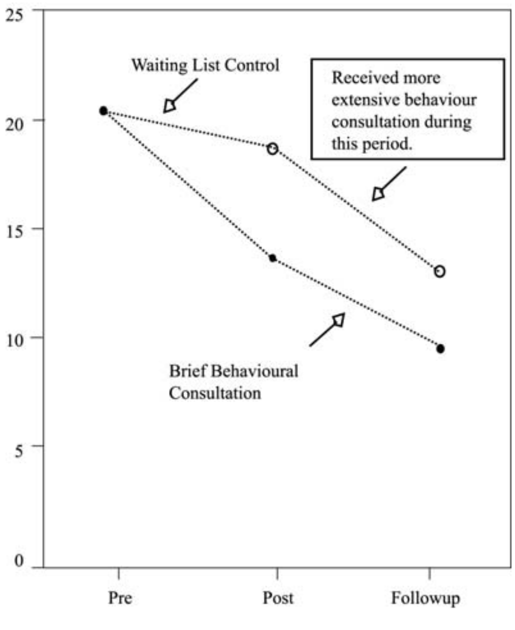
A similar result was found for changes in consultees' ratings on the PBSS as shown in Figure 2. The ANOVA for repeated measures showed a significant effect for time, $F(1, 37) = 30.9$, $p< .001$ and a significant group by repeated measure interaction, $F(1, 37) = 9.9$, $p< .001$. From pre- to post-assessment, careproviders in both groups showed declines in perceived stress related to the presenting problems of the client. The significant ANOVA interaction signifies a significantly greater reduction in perceived stress by consultees receiving the brief behavioural consultation than those on the waiting list.

Follow-up

Follow-up measurement of the ABS and PBSS was conducted 18 months after the post-assessment. As previously stated, the small size of the groups at this point due to attrition renders the follow-up results as suggestive only.

Figure 1 shows the continued reduction in consultees' rating of client behaviour occurrence from the post-assessment to the 18 month follow-up. An ANOVA for repeated measures showed a significant effect only for time, *F*(1,9) = 20.0, *p*< .005. As shown in Figure 2, the decline in PBSS scores from pre- to post-assessment continued over the subsequent 18 month period. An ANOVA for repeated measures calculated on the difference between post-assessment and follow-up-assessment found a significant reduction in scores for both groups, *F*(1,20)= 6.82, *p*<.02, but no significant interaction between group and time.

Figure 2. Mean scores on the Perceived Behavior Stress Scales for the Brief Behavioural Consultation and the Waiting List Control groups at pre-, post-, and follow-up assessment.



It is important to note that during this 18 months follow-up interval, all consultees in the WL group received more extensive behaviour services. The comparison at the follow-up point is reflective of differences between subjects who received brief behavioural consultation 18 months previously and consultees who were on the waiting list and subsequently received more intensive behaviour intervention. Both groups showed continued gains, with no differences found between the groups.

Request for Further Service

On completion of the brief behavioural consultation, 63.2% of consultees indicated that they wished no further service. In comparison, only 5.6% of consultees in the waiting list control group opted not to continue to wait for services when contacted at post-assessment. This difference was highly significant, $\chi^2(1)=13.4$, $p<.001$.

Discussion

After three sessions of brief behavioural consultation, consultees showed significantly greater reduction in their perception of both the frequency of client behaviour problems and the stress caused by those behaviours compared to consultees on a waiting list. There was suggestion that these reductions continued for a further 18 months and maintained at levels not different from results for consultees who were on the waiting list and subsequently received more extensive behaviour services. In addition, more than ten times the number of consultees in the BBC group than in the WL group opted for no further services at post-assessment. Interestingly, this level of consultees opting for no further service was similar to results found after delivery of a six-session brief family therapy (Fisher, 1984).

Because of practical constraints, it was not possible to measure directly changes in client behaviours. It is possible that the more positive consultee perception of client behaviours did not reflect an actual decline in the occurrence of those behaviours. Even if such a result was found, obtaining changes in consultees' perception of behaviour problems would be an important outcome. Clients with developmental disabilities tend not to refer themselves to a mental health clinic, but are referred by consultees who perceive that the offending behaviour needs to be changed. A significant reduction in consultee perception of client problem behaviour may signal a more accepting attitude towards client adjustment, if not an actual improvement in client behaviour.

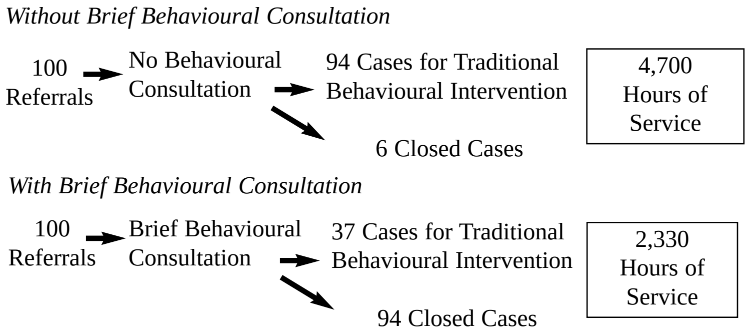
The relatively small sample size of the groups and the use of only one clinical setting may limit the generality of the study. It is unclear if the obtained results would be found with other consultees or clients referred to other behavioural services. A further limitation of the results is the lack of extensive information on the reliability and validity of the PBSS. Further evaluation of the psychometric properties of this measure will need to be undertaken.

The higher level of consultees in the BBC opting for no further service may reflect their dissatisfaction, rather than satisfaction with the services received. If so, one would have expected that during the follow-up period, consultees in the BBC group would have reported having received more additional services than consultees in the WL group. At the 18 months follow-up point, consultees in both groups were asked whether during the intervening period they had referred clients for additional mental health services. Of the 8 respondents in the BBC group, only 2 reported a referral had been made for additional services in the 18 months between the post- and follow-up assessments; in comparison, 5 of the 12 consultees in the WL group subsequently received more extensive behavioural intervention.

One of the major benefits of brief behavioural consultation was an increase in service efficiency. A much greater percentage of consultees who had received brief behavioural consultation opted for no further service than those on the waiting list, resulting in a considerable saving of service hours. Figure 3 illustrates this point further: Consider a hypothetical 100 referrals when brief behavioural consultation is and is not offered as the initial intervention for all consultees. When brief behavioural consultation is not offered, the 100 hypothetical consultees would all be placed on a waiting list. With an estimate that 5.6% of these consultees would no longer wish services when later contacted, approximately 94 of the original referrals consultees would move on to receive more extensive behaviour intervention. If more extensive behaviour intervention takes approximately 50 hours of service per consultee, then the total service hours for those 100 referrals would be 4,700 (94 consultees x 50 hours per consultee).

In contrast, each of the 100 hypothetical clients could be provided with brief behavioural consultation at a mean of 4.8 hours each (total of 480 hours). Given the results of this study, one would expect 37 of the 100 hypothetical consultees would request more extensive behaviour intervention in addition to the brief behavioural consultation. The number of hours to provide the more extensive behaviour consultation would be approximately 1,850 (37 consultees x 50 hours per consultee). This amount added to the time taken to do the brief behavioural consultation would total 2,330 hours - less than half that of not providing a brief behavioural consultation. These savings in service hours then could be reinvested into working with those individuals who require the more intensive interventions.

Figure 3. Service hours with and without brief behavioral consultation for 100 hypothetical referrals.



It is not clear how brief behavioural consultation works. The participation of those who are involved in implementing an intervention in its development maybe a critical component to ensuring follow through of intervention strategies (Brazerman, Giuliano, & Appelman, 1984). Training consultees in the process for program development has been found to result in generalized improvement of the presenting problems (Hundert & Hopkins, 1992; Peck, Killen, & Baumbart, 1989).

It may have been that brief behavioural consultation enables consultees to formulate their own intervention ideas based on provided planning frameworks by the consultant and later honed by the consultant through a collaborative process. The importance of a collaborative consultative process in consultation has been emphasized (Idol & West, 1987; Phillips & McCullough, 1990).

Brief behavioural consultations may not be appropriate for consultees who are not able to problem-solve and implement ideas that emerge after a consultation and may not be suitable in situations where: (a) there is no consultee to implement a strategy (e.g., adults with developmental disabilities living on their own); (b) there is critical need to provide immediate and intensive interventions (e.g., severe self-injurious behaviours); and (c) there are extraneous factors that profoundly impede the consultee’s capacity to develop and/or implement programming ideas (e.g., alcohol abuse, spousal abuse).

Models of community-based behavioural services need to include a range of service options to meet the range of client and consultee needs. In offering only a restricted range of service options, high intensive interventions may be provided to consultees and clients when less intensive interventions may be equally effective. As a result, long waiting lists and services inefficiencies are likely to develop. Brief behavioural consultation does not replace more extensive forms of behaviour consultation, but expands the range of service options.

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Appendix 1

Perceived Behaviour Stress Scale

This scale asks you to indicate the extent of stress is caused by the behaviours of the individual whom you are referring for help. Please rate each of the items by circling the number that best describes how you feel. REMEMBER: There is no right or wrong answer.

Name _____________ Date ____________________

To what extent do you agree with the following statements about the behaviour of the individual you are referring for help.

	Definitely Not	*Not So Much*	*Somewhat*	*Definitely*	*Very Definitely*
1. I need immediate help managing this problem.	1	2	3	4	5
2. I worry about the negative effect this individual is having on others.	1	2	3	4	5
3. I am at wits end, knowing how to deal with this person.	1	2	3	4	5
4. This problem is causing a lot of stress on myself and others.	1	2	3	4	5
5. I feel things will get worse unless this behaviour is corrected.	1	2	3	4	5

A Prospective Study of Out-of-home Placement Tendency in Families of Children with Autism

Adrienne Perry and Anne Black

Abstract

Little is known about the process parents go through in deciding to seek out-of-home placement and to what extent the process is affected by particular child characteristics, family characteristics, and support services received. This study examined, at Time 1, the "placement tendency" of 20 parents of children with autism living at home, that is, how far along a continuum of planning for out-of-home placement parents were. Follow-up data were collected 18 months later (Time 2) on the incidence of actual out-of-home placement, which was examined as a function of variables measured at Time 1. The results indicated that placement tendency scores significantly predicted who had, in fact, placed their child outside the home. However, few of the services or subjective variables parents had reported as being helpful in coping with the child at home actually differentiated between families who had placed and those who had not.

Over at least the past two decades, the trend among those working with children with developmental disabilities (DD) has been to move increasingly towards deinstitutionalization and noninstitutionalization. A clinical assumption is frequently made that providing enough services and/or the right kind of services will prevent families from seeking out-of-home placement or, at the very least, delay the decision significantly. Appropriate educational programs for children with DD as well as various respite and support services for their families have been available for at least a decade in most jurisdictions. Yet a considerable number of families continue to seek out-of-home placement (albeit in smaller settings in the community). Clearly greater understanding is needed regarding the questions of who places whom and why and, in particular, what services and/or other factors help families cope effectively and keep their child at home.

Literature from the 1960s and 1970s comparing children who were institutionalized to those living at home (reviewed by Blacher & Bromley, 1990; Seltzer & Krauss, 1984), indicated that, in general, institutionalized children were likely to be older, male, white, of higher socio-economic status (SES), and from larger families. The severity and nature of the child's DD was also found to distinguish between home and placed groups, specifically: severity of mental retardation, degree of maladaptive behaviour, and level of caretaking required (e.g., self-care skills, physical handicaps). However, there are several methodological problems with these earlier studies. Most were retrospective studies using very heterogeneous samples at some (often considerable) time after placement had occurred. Furthermore, the societal values, professional philosophy, and availability of education and services have all changed significantly since that research was conducted.

More recent studies comparing families of children (or adults) with DD living at home to those with children in residential placements have consistently identified maladaptive behaviour as one of the most powerful predictors of placement (Blacher, Hanneman, & Rousey, 1992; German & Maisto, 1982; Rousey, Blacher, & Hanneman, 1990; Sherman, 1988). The child's increasing age is also typically associated with placement (Blacher et al., 1992; Rouseyet al., 1990; Sherman, 1988; Wynne & Rogers, 1985). Sherman (1988) found larger families and single mothers more likely to have placed their children (see also German & Maisto, 1982). More subjective and emotional variables related to placement were included in a study of 63 families of children with severe disabilities who had been placed within the previous 2 years (Bromley & Blacher, 1991). When parents were asked what had influenced them to place their child when they did, the most frequent responses were daily stress, the child's level of functioning/future potential, and the child's behaviour. When asked what had prevented them from placing sooner, responses frequently reflected parents' attachment to the child and feelings of guilt about potential placement (Bromley & Blacher, 1989). These studies, though more methodologically sophisticated than the earlier work and reflecting a more current social situation are, nevertheless, still retrospective.

Only recently have researchers turned their attention to placement issues in families whose children still live at home. Three prospective studies, using multiple regression designs, have focused attention on predicting placement status on the basis of demographic, diagnostic, and service-related variables. Cole and Meyer (1989) divided families of 103 children with severe DD (aged 4 to 19 years) into three groups according to their placement plans and examined predictors of this classification. Plans to keep the child at home indefinitely were predicted primarily by family resource variables, and secondarily by child characteristics. Plans to keep the child at home during childhood and seek placement around age 21 were predicted by child characteristics and formal support. Plans to seek placement sooner than age 21 were predicted only by the child’s level of functioning. Tausig (1985) examined a host of variables (client characteristics, family characteristics, general stressors, and specific stressors) in 110 families of persons with DD who were requesting out-of-home placement and 137 not requesting it, as a function of whether the person with DD was under or over 21 years. There were only four significant predictors in the younger group: behaviour problems, number of disabilities, disruption of family relations, and family mental health problems, and only one in the adult group, disruption of family relations. In the third study, the urgency of requests for community residential placement was examined in a study of 571 families of young adults (aged 20 to 24 years) living at home (Black, Molaison, & Smull, 1990). Urgency was predicted by three variables: the number of caregiver stressors, the number of reasons cited for the request, and the number of frequent maladaptive behaviours of the young adults.

These three studies of families whose member with DD remains at home are difficult to summarize because of differences in focus, variables, samples, and statistical properties. The proportion of variance accounted for, though significant, was never greater than 45%, suggesting additional important variables were omitted and/or that the measures used were psychometrically weak. Although there is increasing conceptual consensus about what general categories of variables are important (child characteristics, family variables, supports/services), there are as yet no conventionally accepted instruments for measuring these variables or placement likelihood.

The work of Blacher and her colleagues over the past few years reflects considerable progress in the conceptualization and measurement of placement likelihood and related factors. In the context of a longitudinal, prospective study, Blacher (1990) developed a scale for interviewers to rate a family’s likelihood of placement in a standardized way. Called the Placement Tendency Index (PTI), it is simply a 6-point ordinal scale consisting of “stages” families may go through in the process of deciding to place their child. Blacher and Hanneman (1993) now have collected four panels of longitudinal data using this measure in families of 100 children with severe DD who (at the beginning of the study) were 3 to 8 years old and living at home. Several clear patterns were noted. Some families consistently reported no intention of placement and this did not change over time. Families in the middle of the spectrum moved backwards and forwards to some extent, but over time progressed in a linear fashion towards increasing placement tendency. Once families reached 4 or 5 on the scale, placement was virtually assured within one to two years. Of 33 families who had placed their child (or were about to) by the fourth round of data collection, about two-thirds fell into this linear progression pattern, whereas the other third had some triggering event or crisis which precipitated the placement decision (Blacher & Hanneman, 1993). To better measure the various subjective and service-related factors related to placement decisions, Bromley and Blacher developed the *Factors Influencing Placement Scale* (Bromley & Blacher, 1991) and the *Factors Preventing Placement Scale* (Bromley & Blacher, 1989). Both have 20 items answered on a 5-point Likert scale indicating how important parents perceive that item to be in influencing or preventing placement.

Many clinical services accessed by families of children with DD might be expected to decrease placement tendency. Direct services for the child such as educational programs, specialized therapeutic or training experiences, and even generic services may potentially alter the child characteristics which parents find stressful. At the same time, these services may provide secondary respite to families (Blacher & Prado, 1986; Perry, Burke, & Lynch, 1994; Salisbury, 1986). In addition, family support services, such as parent training, parent support groups, individual supportive counselling, and marital therapy are intended, at least in part, to strengthen and support families' coping abilities so that they can raise their child at home. Services such as these have not typically been included in studies of placement.

Respite care is a service specifically intended and widely assumed to reduce stress and prevent placement (Cohen & Warren, 1985). Unfortunately, solid empirical evidence for this clinical assumption is in short supply (Intagliata, 1986; Perry, 1991). In program evaluation studies, families using respite care typically reported it to be very helpful and a substantial proportion reported that they would seriously consider out-of-home placement were it not for respite care (Apolloni & Triest, 1983; Cohen, 1982; Joyce, Singer, & Isralowitz, 1983). However, this kind of evidence is limited by expectancy effects, cognitive dissonance, sampling biases, poor measures, lack of pre-respite measures, and other methodological problems (Perry, 1991).

Conversely, some evidence exists that suggests that respite care may function as a kind of "trial placement" (Blacher, 1990). It may be used by parents who have already decided to place the child out-of-home but who are awaiting the availability of a suitable placement (Bottuck & Winsberg, 1991). Also, under some circumstances, respite care may function as a transition to out-of-home placement (New York Cerebral Palsy Association study by Cohen [1980] described by Cohen and Warren [1985]).

It is important to note that clinical samples of parents who use respite care tend to have children who are more dependent, have lower developmental levels, and more severe maladaptive behaviour than those of nonusers (Factor, Perry, & Freeman, 1990; German & Maisto, 1982; Grant & McGrath, 1990; Halpern, 1985; Marc & MacDonald, 1988). These are, of course, the same characteristics that are related to out-of-home placement. Furthermore, families who use respite care have been reported to have less tangible support (e.g., babysitting) from extended family and friends (Cohen & Warren, 1985; Factor et al., 1990; German & Maisto, 1982; Halpern, 1985; Robinson, 1987). Results of these studies comparing (self-selected) users and nonusers of respite care may appear to support the transition notion. However, it is impossible to determine whether respite functions as a mediating variable or whether the cluster of child characteristics and support variables is independently correlated with respite use on the one hand and placement tendency on the other, thus producing a spurious correlation between respite use and placement tendency.

The relationship between respite care use and placement tendency, therefore, appears paradoxical: respite is intended to reduce placement but may, in fact, lead to placement. Based on our clinical experience, it seems likely that respite users are not a homogeneous group and that the effect of respite depends on why and how the family uses it as well as all the variables investigated in the literature.

To our knowledge, there are no published studies of placement likelihood in a sample of children with autism and pervasive developmental disorder (PDD), specifically, although several studies have included some subjects with autism among other children with DD (Bromley & Blacher, 1989, 1991; Sherman, 1988; Wynne & Rogers, 1985). Because children with autism are often also mentally retarded, they may share many characteristics related to out-of-home placement with other DD groups. In addition, however, children with autism might be expected to be at particularly high risk for placement because of their social unresponsiveness and poor communication skills which might impair parent-child attachment. In addition, the frequency and severity of behaviour problems in autism might also predispose these children to be placed in out-of-home settings. Some support for this assumption was found in a retrospective study by Sherman (1988), who found three times the frequency of autism in the placed group versus the group living at home (21% and 7% respectively), whereas there was no difference in any other diagnostic category examined (i.e., cerebral palsy, epilepsy, mental retardation, neurological disorders).

In the present study, we extended placement research to a sample of families of children and adolescents with autism or PDD. The study was prospective, in that we initially studied families whose children were living at home (Time 1). Furthermore, we report follow-up data on actual out-of-home placement 18 months later (Time 2) to determine whether the variables which parents had reported at Time 1 were helping them prevent placement were, in fact, related to actual placement decisions. Both placement likelihood measured at Time 1 and actual placement at Time 2 were examined in relation to three sets of factors measured at Time 1: demographic and diagnostic variables, services being received, and subjective factors reported by parents.

Higher placement likelihood was expected to be related to older age of the child, lower cognitive level, lower adaptive skills, frequency of maladaptive behaviour, larger families, and in single- versus two-parent families. In terms of services, we expected that access to, and use of, respite services, direct programs/services for the child, and family support services, would be associated with lower placement tendency. Finally, we explored what subjective factors parents reported as helping them maintain the child at home, and to determine ways in which these factors related to placement tendency. These subjective factors included various sources of support, beliefs and feelings about placement, and feelings of attachment to the child.

Method

Participants

Twenty-seven families receiving services from TRE-ADD (Treatment, Research, and Education for Autism and Developmental Disorders) at Thistletown Regional Centre in Toronto, and whose child was currently living at home were invited to participate in the study. Informed consent was obtained from 20 parents (19 mothers; 1 father) or 74% of the eligible families. Of the seven non-participants, two refused and the others did not return the consent after one follow-up call. Ethical considerations prevented us from further prompting participation because families in TRE-ADD are free to decline to engage in any research study. Based on our knowledge of the children and families, there were no obvious demographic or diagnostic differences between participants and non-participants. Twelve of the families (60%) were immigrants to Canada, of which three were Asian, three West Indian, three East Indian, two European, and one middle Eastern. There was a wide range of socio-economic status among the families and all the participating parents spoke English.

The children/adolescents included 17 males and 3 females ranging in age from 6 to 23 years (*M*=12.75; *SD*=4.80). Seventeen met the DSM-III-R (American Psychiatric Association, 1987) criteria for Autistic Disorder, two received diagnoses of other PDD, and the remaining child was diagnosed with Attention Deficit Hyperactivity Disorder accompanied by a language disorder and autistic tendencies. According to standardized tests, 2 children fell in the mild mental retardation range, 5 in the moderate, 7 in the severe, and 6 in the profound.

Measures

Placement tendency. Blacher's Placement Tendency Index (PTI) (Blacher, 1990; Blacher & Hanneman, 1993) was used to assess placement likelihood. The PTI consists of 6 ordered categories or "stages" families may go through in the process of deciding to place their child. Possible scores are: 1 ("have never thought about it"); 2 ("occasionally given it a thought"); 3 ("thought about it a lot, but done nothing"); 4 ("thought about it a lot and made inquiries"); 5 ("have taken steps to place"); and 6 ("have placed our child").

Demographic and diagnostic variables. The demographic variables were marital status and family size. Client variables included age, sex, severity of mental retardation, adaptive level, and maladaptive level. These variables were all available from existing files.

Services survey. A questionnaire was constructed listing 20 services, including 7 kinds of respite care, 5 direct child services, and 8 family services. Parents were asked whether they were presently receiving the service (yes/no) and, if so, to rate on a 3-point scale how important that service was in helping them keep their child at home (very important, somewhat important, or of little importance). A total of 14 services were being received by at least some of the sample. For services not presently received, parents were asked whether or not they desired or needed that service (yes/no).

Factors preventing placement. The *Factors Preventing Placement Scale* (FPPS; Bromley & Blacher, 1989) is a 20-item measure, using a 5-point Likert response indicating the degree of influence each item has in helping families keep their child at home. Bromley and Blacher (1989) report good internal consistency, Cronbach's = .82.

Procedure

At Time 1, the second author conducted telephone interviews with parents, lasting approximately 20 to 30 minutes. She discussed the purpose of the study and completed the PTI and Services Survey. The FPPS was then mailed to families to complete at their convenience (all were returned). Demographic and diagnostic information was obtained from the clinical files.

Eighteen months later (Time 2), information was obtained from social workers involved with each family as to whether the child/adolescent was still living at home or had been placed. The two subgroups (home and placed) were compared on variables from the original study (Time 1). No additional data were collected from parents at Time 2.

Results

PTI scores ranged from 1 to 5. As might be expected given the sample, 70% of the families ($n = 14$) reported low placement tendency (PTI scores of 1 to 3). Spearman rank-order correlations of PTI with the continuous variables indicated that the child's adaptive level was significantly negatively correlated with PTI, = -.45, $p<.05$, and the number of behaviour difficulties was significantly positively correlated with PTI, = .45, $p<.05$. That is, parents of children with lower levels of adaptive skills and higher number of behaviour problems reported higher placement tendency. However, the child's age, cognitive level, and family size were not significantly correlated with PTI and the child's sex was also unrelated to PTI. Marital status could not be examined statistically as there were only two single mothers.

Table 1 shows the 14 services being received and parents' ratings of the importance of each service in helping them keep the child at home. The TRE-ADD Parent Relief house, a specialized respite care program, was frequently used (by 14 families) and was rated as very important in preventing placement by 71% of these families. Fifteen children were in the TRE-ADD school program, which was considered by the parents of 13 of these children (86%) to be very important in their ability to keep the child at home. Sixteen children participated in a summer program, and 88% of these parents rated this as very important to their being able to manage the child at home. Of the Family Services investigated, regular participation and partnership with the TRE-ADD staff in treatment planning for their child was reported most often (17 families) and seen as very important (82%).

PTI scores were examined as a function of the total number of services received and the number of services desired/needed. In this well-resourced sample (M=6.5 services received; SD=1.91; range 4 to 11), the number of services currently being received was not related to PTI. However, the number of services desired/needed (M=7.45; SD=2.31; range 2 to 12) was significantly correlated with PTI, = .60, p<.01, indicating that the further along the continuum toward out-of-home placement families were, the more services they felt they needed. For each individual service, the PTIs of families receiving and not receiving it were compared, but none of these differences were statistically significant. However, three observations may be of clinical significance. Of the six families with the highest placement tendency (PTI scores of 4 or 5), all were Parent Relief users, all had their child in a summer program, and none had access to babysitters.

Table 1. Number of parents reporting services received[a] and degree of importance in preventing placement (n=20).

	number	*Degree of Importance*		
	using	*very*	*some*	*little*
Respite Services				
Parent Relief House	14	10	1	3
Other Residential Respite	2	2	0	0
In-home Respite	4	2	2	0
Extended Family	10	6	2	2
Babysitters	6	3	2	1
Child Services				
School Program	15	13	1	1
Summer Program	16	14	2	0
Special 1:1 Program	8	7	1	0
Recreation Program	3	0	1	2
Family Services				
Planning Partnership	17	14	1	2
Case Management	17	9	4	4
Marital Therapy	7	3	4	0
Individual Therapy	5	2	2	1
Parent Training	11	3	5	3

[a] *Six additional services were included in original survey but were not being received by any families currently.*

Responses on the FPPS tended to be at one extreme or the other, so the original 5-point scale was collapsed, as per Bromley and Blacher (1989), such that items could be considered as very important (scores of 5 or 4 on original scale), somewhat important (3), or of little importance (2 or 1) in preventing placement (see Table 2). Items rated by more than half the parents as very important factors in helping them keep their child at home revolved around three themes: feelings of attachment to the child (items 15, 19 and 20); spousal factors (items 1 and 14); and the availability of appropriate educational programming (items 8 and 9). Spearman rank-order correlations of each item score (on the original 5-point scale) with the PTI were computed, but only two were significant. These were item 2, =.58, $p<.01$, indicating the higher a family's PTI, the more likely they reported the unavailability of spaces having prevented them from placing the child; and item 5, =-.39, $p<.05$, suggesting that families who considered their access to babysitters important in preventing placement had lower PTI scores.

Actual occurrences of placement were investigated 18 months following the original data collection, by which time seven families (35%) had placed their children in residential programs (typically community group homes). Five of the six (83%) families reporting high placement tendency (PTI scores of 4 or 5) at Time 1 had placed their children, whereas only 2 of the 14 (14%) reporting low placement tendency (1-3) had done so (Fisher's exact test significant at p = .007). Both of these latter two placements had been precipitated by behavioural crises in the children (one had set fire to the family home, the other had seriously injured his mother).

Families who had placed their children by Time 2 were compared with families whose children remained at home with respect to a number of relevant variables measured at Time 1. The placed children were slightly older than the ones staying at home (means of 14 and 12 years, respectively) and the children placed had a slightly higher number of behaviour problems (means of 5.4 and 4.0, respectively). Other variables, including cognitive level, did not differ. Interestingly, both children whose families had low PTIs but whose behavioural crises had triggered placement had mild mental retardation.

Families who had placed and not placed their children were also compared in terms of services used and needed. The total number of services actually received by the two groups did not differ, but the number of services needed/desired at Time 1 was significantly greater in the group that placed, Mann-Whitney U, $p< .05$. Looking at specific services, none of the families who had placed had babysitters at Time 1, whereas about half of those not placed did (Fisher's exact test significant at p=.04). In addition, 6 of the 7 families (86%) who had placed were users of the Parent Relief program at Time 1 compared to 61% of the families who had not placed (but this difference did not reach statistical significance).

Table 2. Number of parents reporting degree of importance of items from factors preventing placement scale (n =20 except where noted)

	Degree of Importance		
	very	*some*	*little*
Spouse's Attitude to Placement	14	2	4
No Placements Available (*n* =19)	5	0	14
Child Not a Problem (*n* =19)	7	1	11
Availability of Respite	9	2	9
Availability of Sitters	6	1	13
Siblings Get Along	8	2	10
Feel Guilty; Bad Parent	7	1	12
Appropriate Schooling	12	2	6
Skills Learned at School	13	3	4
Don't Know How to Find	4	1	15
Religious Beliefs	0	2	18
Professionals' Advice	2	0	18
Can't Find Nice Enough Placement	5	3	12
Spouse Helps	12	3	5
Very Attached to Child	19	0	1
Friends' Advice	2	1	17
No More Difficult than Siblings (*n* =19)	6	4	9
Someone Else Raising My Child	9	1	10
Child Wouldn't Understand	11	0	9
Wouldn't See Child	10	0	10

Scores on individual items of the FPPS at Time 1 were examined for families who had placed versus those who had not placed their children. Most items were not related to actual placement. The only clear difference was on item 2 (no placements were available), Mann-Whitney U, $p < .001$). All five families who indicated at Time 1 that this was a strong reason they had not yet placed, did eventually go on to place their child.

Discussion

This study examined actual out-of-home placement in families of children with autism as a function of demographic and diagnostic variables, services and subjective factors parents perceived as related to keeping the child at home, and their placement likelihood up to 18 months before placement occurred. It is the first study to examine these issues in a sample of families of children with autism or PDD, specifically.

The results on actual incidence of placement as a function of Time 1 PTI scores are quite similar to those of Blacher and Hanneman (1993) in several ways, and provide additional support for the predictive value of the PTI. Virtually all families with PTI scores of 4 or 5 in our study went on to place their child out of the home within 18 months. These high PTI families represented about two-thirds of those who did place. The other one-third were families with fairly low placement tendency who placed somewhat suddenly in response to a clinical crisis. Overall, about a third of Blacher and Hanneman's (1993) sample had been (or were about to be) placed by the end of their fourth panel of data collection (about six years from the beginning of their study); the same proportion of our sample was placed in less than two years. This discrepancy may be related to the age difference between samples (their oldest children were young adolescents and ours were in their 20s, which is a more normative time for placement to occur); diagnostic differences between the two samples (perhaps the autism in our sample did, in fact, precipitate placement sooner, although both groups were severely handicapped); different services available; and/or different sociocultural characteristics of the samples.

Consistent with recent literature (Blacher et al., 1992; Black et al., 1990; Rousey et al., 1990; Sherman, 1988; Tausig, 1985) it was not the child's level of cognitive functioning but, rather, his or her level of dependence and difficulty (i.e., adaptive behaviour and maladaptive behaviour) which was associated with higher placement tendency and/or actual placement. These characteristics may, of course, be partially related to the diagnosis of autism in the present sample. However, contrary to prediction, the child's age was not related to placement tendency scores, although children actually placed tended to be older. It is likely in a sample such as this that level of difficulty usurps any linear effect of age (Bromley & Blacher, 1991).

Parents reported that many of the services they were receiving were helping them to raise their child at home rather than seeking out-of-home placement. Direct child services (specialized educational program, summer programs, and specialized therapies) were considered very important in preventing placement and the two school-related items on the FPPS were also rated as very important. Traditional family support services such as case management, supportive counselling, marital therapy, and parent training were also reported to be somewhat to very important in helping parents cope with raising their child at home. The importance of the partnership between parents and program staff in planning and goal-setting for the child may be a function of the sense of optimism about the child's future potential fostered by this process which, in turn, affects parents' plans regarding placement (Bromley & Blacher, 1991). Respite care was considered very important by parents in this sample, as expressed in both the Services Survey and the FPPS. The predominant type of formal respite used, the TRE-ADD Parent Relief program, was rated at Time 1 as very important in preventing placement by the majority of the families who used it. Informal respite care, provided by relatives or ordinary babysitters was less commonly used or available and, even when used, was less frequently rated as very important in preventing placement. This may be a reflection of parents' perceptions of the level of expertise and dependability of such persons in contrast with the more formal respite service, a phenomenon we have encountered in another sample as well (Perry et al., 1994).

Our findings may shed some light on the paradoxical relationship between respite care and out-of-home placement mentioned earlier. There appear to be two distinct patterns or subgroups within the data. Of the seven families who went on to place their child, five had reported on the FPPS at Time 1 that the lack of availability of placements had prevented them from placing their child. Six of these families were using the Parent Relief program at Time 1; none had babysitters. This particular cluster of results suggests that, for this subgroup (one quarter of the sample), use of respite care may well have been a transition stage between caring for the child at home and residential placement. Indeed, in our program, we might encourage use of Parent Relief as an interim coping strategy for families awaiting placement. Interestingly, the only family with a high PTI score at Time 1 who had not placed their child by Time 2 had started using the Parent Relief program. For the majority of the sample, however, placement was not regarded as imminent and availability of placements was not an issue. About half of these families used the Parent Relief program and about one-third had babysitters. For this subgroup of families, we speculate that respite care may be functioning quite differently and serving its intended purpose.

The Factors Preventing Placement Scale, while overlapping to some extent with the Services Survey, provided additional useful information about parents' feelings and values about placement. Three sets of items appeared to be most important to this group of parents: feelings of attachment to the child and/or guilt about placement, spousal support, and educational programs. Responses in the present sample of children with autism/PDD were substantially similar to those reported by Bromley and Blacher (1989).

It should be emphasized that very few of the services or the FSPP items measured at Time 1 clearly distinguished between those families who went on to place and those who did not. Families who placed tended to have children who were older and had more behaviour problems; did not have access to babysitters; tended to use respite care; desired more services than other families; and had cited placement unavailability as an issue. However, none of the other factors parents perceived as important at Time 1 in helping them keep their child at home (e.g., attached to child, good school program, etc.), were statistically related to actual placement. We interpret these data to mean that parents were very satisfied with the services they were receiving, and may have believed they were preventing or delaying placement. However, as noted earlier regarding the respite care literature, studies based on parent perceptions and speculations have been criticized for being open to a number of serious biases, including cognitive dissonance and expectancy effects (Perry, 1991). The results of the present study provide an empirical demonstration of this problem by comparing perception data to objective longitudinal data. The reality of which families placed their children was not well predicted by parents' perception data up to 18 months prior to placement. Thus, caution must be exercised in the interpretation of studies based solely on parental perceptions.

The results of the present study can be brought to bear on the clinical assumption that provision of sufficient levels and appropriate types of services to families will prevent out-of-home placement. Parents in the study who subsequently placed their child reported a greater need for additional services than did other parents, but they received only the same number of services. Although this implies that additional services may have prevented these placements, this is by no means clear, first, because these families were receiving a very high level of service, and second, because receipt of specific services was not related to actual placement. One piece of anecdotal evidence is that, following the initial study, several services identified as desired or needed by a number of families were, in fact, offered (parent information group, sibling support groups, more specialized individual therapies for children, crisis intervention training for parents). The families with high PTI and/or who went on to place their child generally did not avail themselves of these services. It could be the case that these services came too late, but might have helped had they been available sooner. Alternatively, other factors such as personality traits, coping styles, and additional family stressors, none of which was studied here, may moderate and/or interact with the effects of services (Perry, 1989).

The study has several broad clinical implications. First, the results from the FPPS regarding parents' feelings of attachment to the child and guilt about placement need to be taken seriously. Clinicians should be careful not to cause or contribute to parents' guilt but, rather, to help parents, at each stage in the family life cycle, develop formal and informal supports and express their feelings regarding this difficult and complex matter. This includes respecting parents' decision to place their child in a residential setting and making it as constructive a process as possible for all concerned. Other clinical implications include recognizing the potential benefits of developing a wider range of respite options for families, including the use of more generic programs and services. Agencies could benefit families greatly (and in a cost-effective manner) by providing information, training, and support to staff of generic community programs; by providing volunteer opportunities to students in direct care disciplines (many of whom are required to complete a certain number of volunteer hours); and by compiling a roster of trained and reliable babysitters. Finally, the respite value for parents of services provided directly to the child should not be overlooked.

This study, like others, has its strengths and weaknesses. It is one of a small body of prospective studies examining the construct of placement tendency (Blacher, 1990) and its correlates prior to out-of-home placement. It extends such placement research to a sample of parents of children with autism/PDD, a group not specifically studied previously. Furthermore, it provides short-term longitudinal data on actual incidence of placement 18 months following the original data collection.

The families studied, however, represented a small, ethnically diverse (though not necessarily unrepresentative of Toronto), clinical sample, and the generalizability of the findings is uncertain. Statistically, both Type I error and, particularly, insufficient power may be problems because of the sample size and number of analyses. On the other hand, several clearly significant findings were reported, suggesting the power issue was not fatal; furthermore, the pattern of results was internally consistent as well as being relatively consistent with the literature, suggesting the results were not attributable to Type I error or chance.

It remains for further research, preferably multivariate and longitudinal in nature, using both subjective and objective measures, to replicate these results and to address the many remaining questions regarding out-of-home placement in families of children with autism and other developmental disabilities.

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The Conceptualization and Measurement of Quality of Life: Current Status and Future Considerations

Robert L. Schalock

Abstract

The concept of quality of life has emerged as an overriding principle to improve the lives of persons with disabilities and to evaluate the social validity of current rehabilitation services and supports. This article integrates work over the last five years which is related to the conceptualization and measurement of the quality of life concept. Key components of this integration include core quality of life dimensions, core dimension exemplars, measures built around the core dimensions and exemplars, and three measurement techniques. The article concludes with a number of specific questions and potential answers regarding the concept's conceptualization and measurement.

Quality of life is not a new concept, and indeed people since antiquity have pursued the dimensions of a life of quality. Within the field of mental retardation and developmental disabilities, the concept of quality of life has emerged as part of the current paradigm shift characterized by:

- A transformed vision of what constitutes the life possibilities of persons with disabilities. This view includes an emphasis on self-determination, strengths and capabilities, importance of normalized and typical environments, provision of individualized support systems, enhanced adaptive behaviour and role status, and equity (Luckasson et al., 1992).
- A supports paradigm that underlies service delivery to persons with disabilities and focuses on supported living, employment and inclusive education (Bradley, Ashbaugh & Blaney, 1994; Smull & Danehey, 1994).

- An interfacing of the concept of quality of life with quality enhancement, quality assurance, quality management, and outcome-based evaluation (Albin, 1992; Buckley & Mank, 1994; Schalock, 1994).

Unfortunately, people with disabilities are vulnerable to shifting social, political and economic trends. For example, the current social transformation is predicted to result in a 21st century characterized by: an economic order in which knowledge, not labour or raw materials or capital, will be the key resource; a social order in which inequality based on knowledge is the major challenge; and a public policy in which government cannot be looked to for solving social and economic problems (Drucker, 1994).

What general principle for people with disabilities should underlie these current social, political, and economic transformations? I would suggest that the concept of quality of life provides a fundamentally positive and growth-oriented principle that can be the basis for developing a national and international policy towards people with disabilities. The concept of quality of life steers us in the right direction: towards person-centred planning, supporting people's needs and desires, and asking people what they think and how they feel.

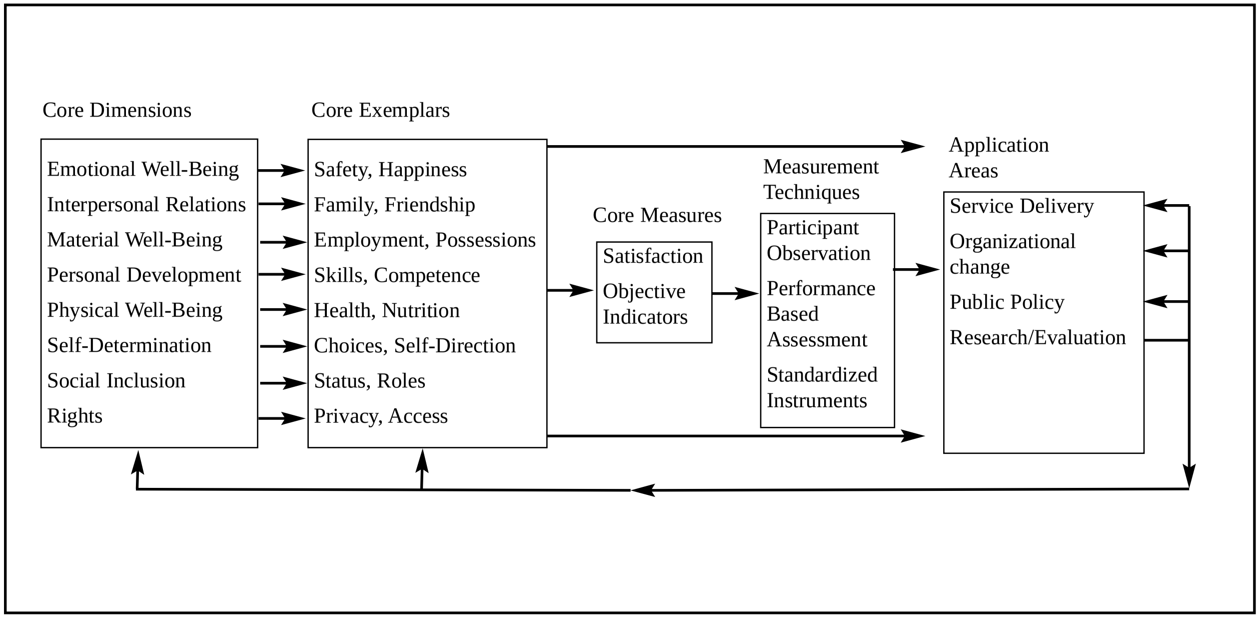
To this end, the present article has two goals. First, it will integrate work over the last five years which is related to the conceptualization and measurement of the quality of life concept. Second, it will suggest the focus and direction of future efforts. Throughout the presentation, the heuristic quality of life model presented in Figure 1 will be used. The model's five components include: core quality of life dimensions, core dimension exemplars, measures that are built around the core dimensions and exemplars, measurement techniques, and application areas. Because of page constraints, application areas will not be discussed. A detailed discussion of these can be found in Schalock (1997a).

Present Status

Core Quality of Life Dimensions

Considerable work has been done over the last five years identifying the core dimensions of a life of quality. Based on that work (Campbell, Converse & Rogers, 1976; Cummins, in press a; Dossa, 1989; Felce &

Figure 1. A Heuristic Quality of Life Model



Perry, 1996; Flanagan, 1982; Gardner & Nudler, 1997; Hughes & Hwang, 1996; Keith, Heal & Schalock, in press; Schalock, 1990, 1996a), eight core quality of life dimensions have emerged:

- Emotional well-being
- Interpersonal relations
- Material well-being
- Personal development
- Physical well-being
- Self determination
- Social inclusion
- Rights

Core Quality of Life Exemplars

If the concept of quality of life is to be used as an organizing concept in public policy and service delivery, then objective indicators or exemplars need to be developed for each core quality of life dimension. When this is done, we can: overcome some of the problems involved in using only subjective measures (Felce & Perry, 1996); provide objective indicators that are comparable across people (those with disabilities and those without), programs, and potentially cultures (Keith, 1996; Schalock, 1997b); and use quality of life indicator data to develop or change service/support programs, assess service outcomes, and evaluate public policy (Schalock, 1995).

The attempt to identify quality of life exemplars began with the work of Andrews and Whithey (1976) and Zautra and Goodhart (1979) and has continued with the work of Cummins (in press a), Gardner and Nudler (1997), Heal and Seligman (1996), Renwick, Brown, and Nagler (1996), and Schalock (1996a). An initial list of exemplars associated with each of the eight core quality of life dimensions is presented in Table 1.

A number of criteria for developing these exemplars should guide our future work in this area. Chief among them include : the indicator is valued by the person; multiple indicators are used; the indicator is measurable, with demonstrated reliability and validity; the indicator is connected logically to the program, service, or support; and the indicator is evaluated longitudinally (Schalock, 1995).

Core Measures

There is a growing consensus that there are two core measures of quality of life: satisfaction and/or objective indicators of the core exemplars summarized in Table 1.

Table 1. Quality of Life Exemplars

Dimension	*Exemplary Indicators*	
Emotional Well-Being	Safety Spirituality Happiness	Freedom from Stress Self Concept Contentment
Interpersonal Relations	Intimacy Affection Family	Interactions Friendships Supports
Material Well-Being	Ownership Financial Security Food	Employment Possessions Social Economic Status Shelter
Personal Development	Education Skills Fulfilment	Personal Competence Purposeful Activity Advancement
Physical Well-Being	Health Nutrition Recreation Mobility	Health Care Health Insurance Leisure Activities of Daily Living
Self Determination	Autonomy Choices Decisions	Personal Control Self-Direction Personal Goals/Values
Social Inclusion	Acceptance Status Supports Work Environment	Community Activities Roles Volunteer Activities Residential Environment
Rights	Privacy Voting Access	Due Process Ownership Civic Responsibilities

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1. Satisfaction. An essential dependent measure of one's quality of life is the person's level of satisfaction (Campbell, et al., 1976; Edgerton, 1996; Halpern, Nave, Close & Nelson, 1986; Harner & Heal, 1993; Heal &

Chadsey-Rusch, 1985, Heal, Rubin & Park, 1995; Lehman, 1988; Lehman, Rachuba & Postrado, 1995; Medley, 1990). Using satisfaction as the major dependent measure of quality of life has the advantages of: providing a common language that can be shared by consumers, providers, policy makers, regulators, and researchers; assessing consumer needs; and evaluating consumer satisfaction.

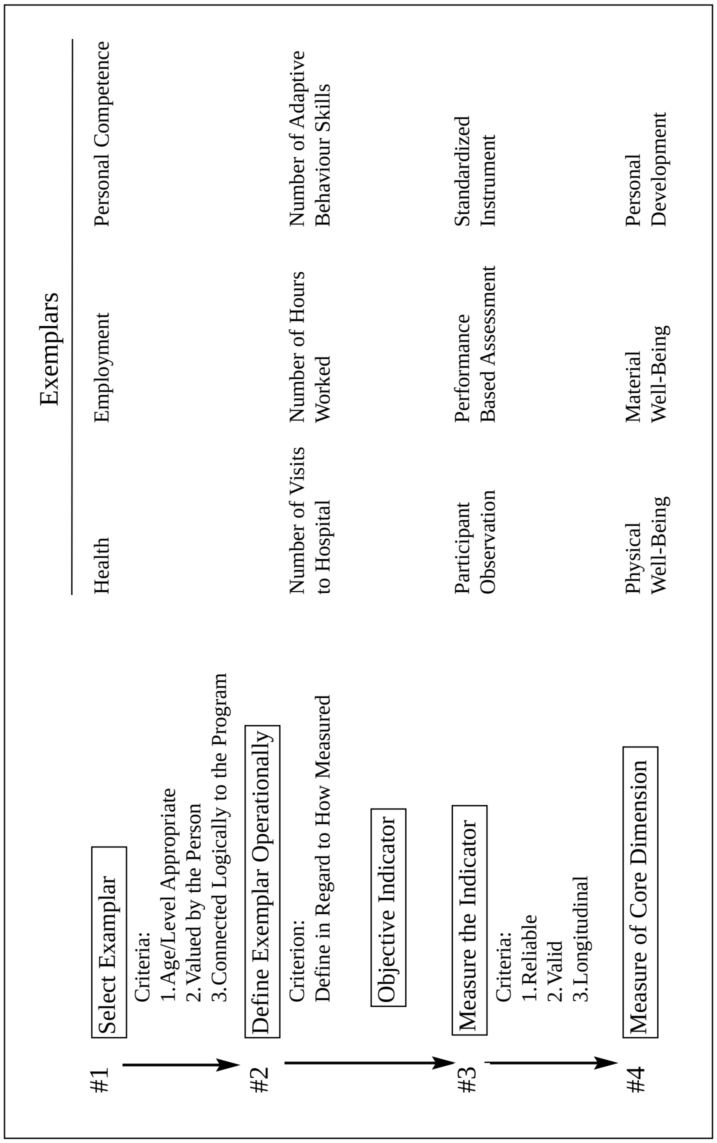
2. Objective indicators of the core exemplars. A person's satisfaction level is a critical--albeit incomplete--measure of one's quality of life. This is especially true in today's world of accountability and "outcome-based evaluation" where both efficiency and value outcomes are required (Schalock, 1995). Thus, core quality of life measures should also include objective indicators, which can be based on one or more of the core exemplars summarized in Table 1.

Moving from an exemplar to an indicator is a straight-forward process. It includes the four steps that are diagrammed in Figure 2. First, select one or more exemplars that meet two criteria: (a) valued by the person and (b) connected logically to the program, services or supports received by the person. Second, define the exemplar operationally. To operationally define something is to define it with reference to how it is measured. Third, measure the indicator. This step involves not just demonstrating reliability and validity, but also includes the commitment to measure the exemplar/indicator longitudinally. Once an exemplar is selected, defined operationally, and measured, it can be considered (Step #4) a measure of the core dimension.

Measurement Techniques

A basic point made repeatedly throughout current work is that quality of life is a multi-dimensional construct. Thus, one or more measurement methods need to be used, depending upon the investigator's focus and purpose. The use of multiple measurement techniques is based on a number of premises including: quality of life is a multi-dimensional construct in which culturally consensual values and shared attitudes are reflected; individuals differ in their ability to understand and respond; people use quality of life data for different purposes including self report, description, evaluation and comparison; and the utilization of quality of life data can focus on either the individual or a group. It is within this context that the following three measurement techniques are proposed.

Figure 2. Developing and Measuring Objective Indicators of Core Quality of Life Exemplars.



1. Participant observation. This measurement technique requires that data collectors observe what people do, listen to what they say, and frequently participate in their daily activities to get a better sense of their life (Edgerton, 1996). This technique also lends itself nicely to attitude surveys regarding life satisfaction, consumer satisfaction, feelings of well-being, and person-environmental interactions. The investigator can also study the behaviour and interactions displayed in natural settings in order to describe in detail the person's life.

2. Performance-based assessment. This second measurement technique is defined as using objective indicators based on core quality of life exemplars to evaluate a person's core quality of life dimensions. Table 1 listed a number of exemplars that can be used as a basis for such assessment. For example, if one is interested in evaluating one's physical well-being, objective indicators such as one's health status, health care coverage, nutritional status, or recreation and leisure activities could be used. On the other hand, one could also use these same indicators to survey or ask the person about how he/she feels about them, or how satisfied they are with them. If this is done, one is then using a participant observation technique. Thus, the same quality of life indicator(s) can be used to evaluate either the "subjective" or "objective" aspect of the core quality of life dimension. What is different is the measurement technique used.

3. Standardized instruments. These instruments are used frequently to assess a number of indicators reflective of quality of life. Specific instruments are summarized in Cummins (in press b) and Schalock (1996b). The most common factors assessed by current quality of life instruments include home and community living, material well-being, employment, possessions, social integration (family, friends, natural supports), health status/safety, personal control, choices, and decision making. Qualities of a good quality of life scale include (Cummins, in press b):

- operationalizes a quality of life definition
- includes both subjective and objective indicators
- comprises domains/sub-scales that broadly capture a life of quality
- involves parallel forms of use with non-disabled populations
- weights domain satisfaction by perceived importance
- includes large sample normative data
- is psychometrically sound

A framework for using one or more measurement techniques is outlined in Table 2. The table is built around the three measurement techniques discussed previously and the eight core quality of life dimensions listed in Figure 1. There are three aspects to the matrix. First, the core quality of life dimensions are listed down the side. Second, across the top are listed the three measurement techniques: participant observation, performance-based assessment, or standardized instruments. Third, the "x" denotes the suggested technique to use to measure the core dimensions.

Table 2. A Framework For Measuring Core Quality of Life Dimensions

Core Dimension	*Measurement Technique*		
	Participant Observation	*Performance-Based Assessment*	*Standardized Instruments*
Emotional Well-Being	X		X
Interpersonal Relations	X		
Material Well-Being	X	X	
Personal Development	X	X	X
Physical Well-Being	X	X	X
Self Determination	X	X	
Social Inclusion	X	X	X
Rights	X	X	

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Future Considerations

As discussed in the previous section, the last five years have seen significant work in the conceptualization and measurement of quality of life. Overall, these last five years can be characterized as a time of increased:

- interest in the concept of quality of life
- research into its critical consensual dimensions
- use of multidimensional measurement techniques
- attempts to incorporate the concept into program delivery and evaluation efforts
- conceptualization of quality of life as a sensitizing and organizing concept.

Despite these efforts, there are still gaps in our knowledge related to its conceptualization and measurement. Suggested questions and possible answers regarding its conceptualization and measurement are discussed in the sections that follow.

Conceptual Issues

Quality of life is a multifaceted construct that has been referred to as a sensitizing concept, a research construct, and/or an organizing concept that provides direction and guidance in our work to improve life conditions of all persons. It is still apparent, however, that a consensual conceptualization of quality of life is still emerging. My understanding of the quality of life literature suggests that four conceptual issues still need to be resolved before a reasonable consensus is reached. Each of these issues is expressed as a question to clarify the issue and stimulate further discourse: (1) How should we refer to the term "quality of life"?; (2) Is quality of life a single, unitary entity, or a multi-dimensional, interactive concept?; (3) How is it best to conceptualize indicators of quality of life?; and (4) Is quality of life the same for all individuals?

1. How should we refer to the term "quality of life"? Currently, there are over 100 definitions and models of quality of life (Cummins, 1995). While Spitzer (1987) found only four articles with quality of life in their titles between 1968 and 1970, Hughes et al. (1996) report 87 studies between 1972 and 1993 that met their research criterion. This rapid increase undoubtedly reflects both the tremendous interest in the concept of quality of life and the lack of consensus regarding its meaning. Thus, the question: Are we better off with a definition of quality of life, or would we be further ahead to consider quality of life as a working construct or organizing concept?

2. Is quality of life a single or multi-dimensional construct? The earlier work on quality of life implied that it is a single or unitary entity that could be expressed as global satisfaction, well-being or happiness. Subsequently, the emphasis has shifted to considering quality of life as a multi-dimensional, interactive construct. For example, Hughes et al. (1996) suggest that environmental factors interact with personal demographic characteristics to influence a person's quality of life. Similarly, Heal et al. (1995) suggest that quality of life reflects global satisfaction with one's life style and control over the human and environmental resources that produce satisfaction. Finally, Zautra and Goodhart (1976) suggest that:

> *quality of life pertains to the goodness of life that resides in the quality of life experience, both as subjectively evaluated and as objectively determined by an assessment of external conditions (p. 1)*

3. How is it best to conceptualize indicators? Historically, there has been a distinction between the objective and subjective indicators of one's life of quality. Subjective indicators focus on the individual's feelings of well-being and satisfaction; objective indicators focus on normative factors such as life style, income, and objective conditions of living. The important conceptual issue to resolve is whether we are better off to continue this distinction, or does it make better sense (as argued in the first section of this article) to consider a number of core quality of life exemplars that can be assessed on the basis of satisfaction or objective indicators.

4. Is quality of life the same for all individuals? Initially, quality of life was referenced to the population at large and thus objective, normative comparisons of quality of life indicators was logical (Andrews & Whithey, 1976; Campbell, 1981; Campbell et al., 1976). In the mid 1980s, the concept began to appear in the mental retardation/developmental disabilities literature and at the same time, Flanagan (1982) suggested that quality of life for persons with disabilities should be evaluated within the context of their condition. This notion was reinforced in the significant work of Borthwick-Duffy (1996) who suggested that:

> *Certainly the evaluation and measurement of life quality must follow a clear delineation of the important dimensions of quality of life, keeping in mind that, regardless of intelligence level, individuals will differ in their preferences and their own perceptions of what constitutes a good quality of life (p. 186).*

Others, however, have raised the question as to whether or not the concept of quality of life should be considered the same for all persons within a given language/cultural grouping. Goode (1990,1994) and Schalock and Keith (1993) suggest that we should conceptualize quality of life similarly for persons with or without disabilities. Similarly, Cummins (1995) states: "It is imperative that all definitions and models of quality of life be referenced to the general population both in their conception and operational measures" (p. 14).

Measurement Issues

The measurement of the quality of life construct has progressed during the last five years as reflected in the general agreement found in the measurement literature about the core quality of life dimensions (Figure 1) and the concordance among quality of life indicators assessed on current measurement instruments. Despite this progress, at least four measurement issues still need to be resolved: (1) What should be measured?; (2) How do we measure quality of life?; (3) What psychometric standards need to be considered?; and (4) How do we overcome measurement challenges?

1. What should be measured? We cannot completely answer this question until we have resolved the first two conceptual issues discussed in the previous section: How should we refer to the term quality of life, and is quality of life a single, unitary entity or a multidimensional, interactive construct? In the meantime, we need to discuss whether it is best to evaluate one or more of the core quality of life exemplars listed in Table 1. Should we continue to use unitary measures (such as global satisfaction, well-being, or happiness)? Or should we continue to make the distinction between subjective and objective indicators? A related issue is whether various dimensions of quality of life should be weighed differentially, as suggested by Felce and Perry (1996) and Cummins (1995).

2. How do we measure quality of life? In their review of the literature, Hughes et al. (1996) found that of the 87 studies evaluated, an interview, questionnaire, or a combination of the two was used in 74% of the studies. I have suggested a two-factor measurement model (Table 2) based on the core quality of life dimensions and three measurement techniques (participant observation, performance-based assessment, and standardized instruments). Other investigators have suggested different measurement models. For example, Heal and Seligman (1996) suggest a measurement taxonomy that includes three components: general method, respondent, and type of instrument. Heal et al. (1995) have also suggested a matrix consisting of three perceivers (individual, intimate acquaintance, or third party) by three perspectives (individual, intimate social relationships, or society at large). The common message in these measurement models is very clear: There is the need to use multiple methods and assess quality of life from a number of different perspectives.

3. What psychometric standards need to be considered? Regardless of the answers to the first two measurement issues, one cannot overlook the need to measure the quality of life construct reliably and validly. A number of key points about necessary psychometric standards need to be stressed. First, the construct must be measured reliably, which requires investigators to demonstrate the consistency of their measures--whether the determination is made for test-retest, inter-/intra-observer, or internal consistency. Second, the construct must be measured validly. Content validity is probably not enough. Investigators need to go one step further and demonstrate construct validity, which answers the question, "Do the items measure the underlying

construct being studied?" This is the measurement issue that makes reaching consensus on the four conceptual issues discussed earlier in this section so important. Unless the quality of life construct and its indicators are conceptualized clearly, then measuring that construct is very difficult. Additionally, if comparisons are made, then the investigator is obligated to develop and present standardization data.

4. How do we overcome measurement challenges? People with disabilities present significant measurement challenges including the use of proxies, the basis for the list of specific life circumstances to be evaluated, the lack of effective communication systems, the potential contamination between the predictor and criterion variables, and demonstrated validity. One also needs to look at the effects of the interview itself. For example, Antaki and Rapley (1995) have recently used conversation analysis to show that the typical administration of quality of life questionnaires involve distortions of the questions brought about by the need to paraphrase complex items, and distortions of answers brought about by interviewers' pursuit of legitimate answers. Similarly, Stancliffe (1995) has reported moderate to low concordance rates between self-reports and reports by proxies.

The following strategies may be need to be used to overcome these measurement problems:

- Use multiple methods to capture the core quality of life dimensions and their indicators in which one is interested.
- Use either-or questions or objective multiple choice questions with three or four options accompanied by pictures (Seligman et al., 1993).
- Correct statistically for response biases (Heal & Chadsey-Rusch, 1986; Harner & Heal, 1993, Heal et al., 1995).

  Use proxies (Heal & Seligman, 1996; Schalock & Keith, 1993).
- Resolve differences between the client and proxy through discussions and detailed behavioral observation (Stancliffe, 1995).
- Rely more heavily on participant observation that encompasses the issues of expressed choices, control and satisfaction (Parsons & Reid, 1990; Realon, Favell & Lowerre, 1990).
- Ensure that there is little or no contamination between the predictor and criterion variables. Two criteria should guide

> our work here: (a) the variables are not correlated and (b) the results are not an artifact of the method used. General guidelines to meet these two criteria include: predictors that do not overlay conceptually; assessments that are separate so there is no articulation or communication between the instruments; and temporal independence between the predictors and the criterion (Schalock, 1995).

In summary, the decade of the 1990s has truly been the "decade of quality of life." It has been, and is, a challenging and highly rewarding time to be in the field of disabilities. In this decade we have seen shifts from:

- services to supports
- programming to opportunity development
- passive to active consumer roles
- process to outcomes
- the individual to the environment
- research questions to policy evaluation
- categorical to non-categorical
- a deficiency to a growth model
- dependency to interdependence
- daily schedules to rhythms of nurturing events
- normalization to quality

These changes have not just happened. They have occurred because, in large part, they reflect both a healthy evolution in our social philosophy, and the changing vision we have of persons with disabilities. Inherent in this evolution and change has been the concept of quality of life – a concept that speaks of equity, value, growth, potential, and good.

Current public policy is undergoing tremendous value clashes. In fact, the 1990s is also referred to as the "decade of value clashes." In the ensuing struggles, the disability community will need to be stronger advocates than ever in the past. In that struggle, the concept of quality of life provides a fundamentally positive and growth-oriented principle that can be the basis for service delivery policy and practices.

But tremendous work lies ahead. Thus, I conclude with six basic action steps that should facilitate our work as we approach the "21st century quality of life agenda":

1. Reach consensus on the core dimensions to a life of quality.
2. Align service delivery with predictors of the core quality of life dimensions.
3. Continue to embrace total quality management.
4. Develop a technology of supports.
5. Align public policy with the concept of quality of life.
6. Evaluate the outcomes from quality of life-oriented public policy.

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Editorial:
Cost-Benefit of Effective Interventions

Maurice Feldman

The Ontario Ministry of Community and Social Services (MCSS) has recently published several documents that chart the future of Ontario's social services, and developmental disabilities services in particular. These position statements include: Making Services Work for People, Individualized Support Agreements, and Reinvestment Strategy for Children and Youth, and Reinvestment Strategy for Adult with a Developmental Disability. In Making Services Work for People, the current government declares its intention to require funded services "to provide supports to those in greatest need, and to provide investment supports to reduce or eliminate the need for future services." Following up on the latter point, the purpose of the reinvestment strategies is "to reduce avoidable personal and social costs to families and the communities and the financial costs to government that arise when children, youth, and adults require long-term or intrusive, expensive services." Thus, these documents reveal that the government expects to see a "return" on its investment of tax dollars, promotes cost-effectiveness, and holds service providers accountable for client outcomes. Although obviously inspired by Mike Harris' fiscally conservative "Common Sense" dogma to funding of services, the documents contain rhetoric that are, nonetheless, consistent with the currently accepted philosophies in developmental disabilities, namely social inclusion and person-centred planning.

The government's initiative assumes that: (a) there are, in fact, cost-effective interventions in developmental disabilities (there are) and (b) the government will encourage (and fund) service providers to offer these interventions, discourage the use of ineffective, unproven, or more costly approaches (when alternatives exist), and inform parents of these services (it's not).

Let us examine two service systems-early intervention and treatment of people with psychiatric/behaviour disorders-that are highlighted in the two Reinvestment publications. Evidence is accumulating that, at least in these two areas, cost-effective interventions are being developed.

Early Intervention for Autism/PDD

As stated in the Reinvestment Strategy for Children and Youth, "research shows that certain services and supports, when provided to families with young children...will help keep the children...and their families from requiring more costly, intrusive or longer-term services." One outstanding example of this research in developmental disabilities is intensive behavioural intervention for young children with autism/PDD. It appears that such early intervention may result in long-term improvement in most participants with about 50% of children fully recovering-i.e., they are indistinguishable from typical peers (Green, 1996; Lovaas, 1987; McEachin, Smith, & Lovaas, 1993). Although more research is needed to verify and replicate its effects, early intensive behavioural intervention (sometimes referred to as the "Lovaas method" or "discrete-trial" training) is currently the only scientifically based treatment for autism/PDD with such impressive, objective outcomes (for more information, please check out FEAT of BC website: http://fox.nstn.ca/~zactam/FEATbc).

Cost-benefit of Intensive Behavioural Interventions

If the results reported by Lovaas and others are replicable, not only is the adverse impact of autism/PDD greatly reduced, but the potential for savings is enormous. If between 30-50% of children with autism/PDD no longer (and never again) show any signs of impairment and the remainder require less intensive supports, then despite the initial costs of the intervention, the savings in family and community support and special education services (that would have been needed without early intervention) should be substantial over the life-time of that individual. A recent report by Jacobson, Mulick, and Green (1996) confirms this obvious supposition (I thank Dr. Adrienne Perry for bringing this briefing to my attention). Using the Commonwealth of Pennsylvania as a model, they estimated that, assuming an initial outlay of US$50,000 per year for 3 years (ages 2-4 years) to provide intensive behavioural intervention (up to 40 hours per week of one-to-one training) and somewhat less effective outcomes than found in the research reports, the cost-benefit savings per individual just to age 45 would be approximately US$1,300,000 (with 3% per year inflation). Clearly, this intervention would be worth the initial allocations.

Adults With Developmental Disabilities and Mental Health Problems

Adults with developmental disabilities and mental health problems are a focus in Reinvestment Strategy for Adult with a Developmental Disability. With the depopulation of Ontario's Schedule 1 facilities and a moratorium on new admissions, increasing numbers of people with development disabilities and behavioural/psychiatric disorders require specialized supports and services in the community. It has been estimated that there are about 85,000 people with developmental disabilities and mental health problems in Ontario (Yu & Atkinson, 1993). A recently completed province-wide survey found an approximate 50% prevalency rate of psychopathology in persons with developmental disabilities living in Ontario (Atkinson, Feldman, & Condillac, 1998).

Cost-benefit of Community Behavioural Support and Crisis Response

Given the intensity and long-term nature of needed services, supporting people with challenging behaviours can be quite expensive. Nevertheless, a recent report from Minnesota found that the combination of intensive behavioural outreach services and multidisciplinary crisis response/unit in the community was far less expensive than alternative services such as institutionalization and hospitalization (Rudolph, Lakin, Oslund, & Larson, 1998). 57% of individuals (n = 14) who were unable to access the special services were institutionalized or hospitalized, compared to only 4% (1 of 24) of clients who received the services (the behavioural challenges were similar in the two groups). Rudolph et al. estimated a savings of US$20,000 per individual over just a 90 day period that clients were placed in the crisis unit; US$9,000 was saved for clients who received the outreach services. Here is another example, where not only is a service effective, but it also is far less costly than current strategies.

Funding Cost-Effective Services

According to the FEATbc website, U.S. based private health insurance companies now recognize intensive early behavioural intervention for children with autism/PDD as medically necessary. In Canada, the Alberta government has been mandated by the court to fund intensive behavioural intervention through the provincial health plan (the actual Alberta court decision can be read at: http://fox.nstn.ca/~zacktam/FEATbc/Alberta.html).

As far as I am aware, despite the rhetoric in the their recent position statements, the current Ontario government does not have a comprehensive plan to fund such interventions for children with autism/PDD through either MCSS or OHIP. In my experience, parents of children with autism/PDD in Ontario often use their own money to hire an expert to design and monitor the intervention. Parents who cannot afford to hire trainers often make extensive use of volunteers who actually do the hands on work with the child. The only government funding that parents have that could be used to defray the costs of intensive early intervention is Special Services at Home and Handicapped Children's Benefits, both of which were not necessarily designed to fund therapy and only cover but a small portion of the costs. The lack of a government plan to fund intensive early intervention for children with autism/PDD is short-sighted and contrary to the vision set out in Making Services Work for People and Reinvestment Strategy for Children and Youth. If the Commonwealth of Pennsylvania experience is applicable to Ontario (and there is no reason to assume otherwise), then here is a chance for the government to "reduce avoidable personal and social costs" by funding a service that truly provides a substantial return on its initial investment. By developing a province-wide plan that assures equal access to intensive early intervention to qualifying and willing families (as is now the case in Alaska and other U.S. states), the provincial government has the chance to do exactly what it says it wants to do-reduce suffering and save taxpayers money.

Likewise, as the provincial government continues to close and depopulate Schedule 1 facilities, it needs to promote accountability based on client outcomes. Funding should be directed to ethical, cost-effective models of community services for people with challenging behaviours. Cost savings alone should not be the primary consideration. Many inexpensive solutions will not work (and ill-conceived, unvalidated methods may ultimately result in far more money being spent than would have been needed if an effective intervention was sought in the first place). Some evidence-based approaches will emerge as being not only more effective, but also more cost-effective. A model, similar to the behavioural support outreach and crisis response service in Minnesota certainly could be implemented in Ontario (McCreary, personal communication, 1997).

Conclusion

In the developmental disabilities sector, at least with respect to early intervention for children with autism/PDD and community services for people with challenging behaviours, there appear to be cost-benefit models that are quite consistent with the provincial government's approach to making services work for people. To my knowledge, at this point there only has been the notorious unilateral funding cuts to social services in the mid-90s, followed by some recent funding increases in respite and infant development services in certain regions. There does not appear to be a comprehensive plan to provide funds to actually implement the reinvestment strategies in areas where there already is research suggesting the potential for substantial benefits and cost-savings. Is the government willing to actually make the investments where they can have a major demonstrable impact?

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Social Competence and Peer Relations in Children With Mental Retardation: Models of the Development of Peer Relations

James M. Bebko, J. Ann Wainwright, Jessica A. Brian, Jennifer Coolbear, Reginald Landry, and Denise D. Vallance

Abstract

This article examines the development of social competence, specifically peer relations and friendships, in children and adolescents with developmental disabilities. Two complementary models are developed from the literature on children without disabilities and provide a framework to examine the literature on peer relations in children with mental retardation. For children with limited peer interaction skills and difficulty developing lasting friendships, the risk is increased for the development of psychological disorders. Children with mental retardation are significantly challenged by the process of establishing lasting peer relationships and satisfying friendships. The potential contribution of social competence difficulties to the increased prevalence of adjustment problems in populations with mental retardation is discussed.

As deinstitutionalization and integration into the community has progressed, an area of increasing concern has been the social competence of individuals with developmental disabilities. In this paper, we adopt Howes' (1988) definition of social competence as behaviour reflecting successful social functioning with peers. According to this definition, social competence is comprised of two related concepts: social interaction and friendships (Howes, 1988). Social interaction skills with peers have been viewed as making a unique contribution to a child's development in a number of domains. Hartup (1983) and others (e.g., Asher, 1983; Ladd, 1988) have argued that social, psychological, and cognitive development are enhanced through a child's interactions with age-mates. Accordingly, children who are less able to interact effectively with other children will have less opportunity to learn typical and effective modes of social conduct, and to develop appropriate social and/or cognitive skills. In addition, children who fail to develop social skills, and who become isolated from their peers, may be at risk for future adjustment problems (Guralnick, 1986). A clear link between lack of peer friendships and maladjustment in childhood and adulthood has been identified (Erwin, 1993; Hartup, 1983).

Children with mental retardation have been identified repeatedly as having significant difficulties in establishing peer relations (Guralnick, Connor, & Hammond, 1995; Guralnick, Connor, Hammond, Gottman, & Kinnish, 1995; Guralnick & Groom, 1985, 1987a, 1987b), as well as having poor social status (Asher & Taylor, 1981; Brewer & Smith, 1989; Gottleib & Leyser, 1981; Rothlisberg, Hill, & D'Amato, 1994), and unsatisfying friendships (Taylor, Asher, & Williams, 1987). These children also exhibit a higher incidence of psychopathology and adjustment problems (Eaton & Menolascino, 1982; Rutter, Graham, & Yule, 1970). In spite of these alarming findings, only a small amount of research has been aimed at investigating peer relations and the development of friendships among children with mental retardation.

The present paper systematically examines social competence and, particularly, peer relations in children with mental retardation. Two models are presented to help organize a review of research on social behaviours in early interactions with parents and in subsequent peer relationships, acceptance by typical children, and the nature of friendships in children with mental retardation. Finally, we will explore attempts to enhance social skills in this population. Because our goal is to draw on the themes that emerge from the typical developmental literature, in these sections we limit our discussion to children with mild to moderate mental retardation. It is likely that those with more profound impairments may have different needs and different opportunities, and that the models we have developed may be of limited applicability. Nonetheless, it is hoped that what is lost in breadth will be gained in coherence. Before embarking on this endeavour, however, the literature on social competence in children and adolescents without disabilities is briefly outlined.

The Beginning of Social Relationships: Parent-Child Interaction

Peer relations do not emerge in isolation—social behaviour first appears in the context of the family. Many authors have argued that early parent-child interactions lay the foundation for relationships throughout life (e.g., Erwin, 1993; Grusec & Lytton, 1988). In this view, the quality of the relationship between parent and child is strongly associated with the development of later social skills, and with subsequent success in the peer culture.

Almost from birth, infants appear to attend and respond preferentially to social stimuli, including the human face (Fantz, 1961; Johnson & Morton, 1991). It has been argued that in the early stages of social development, it is primarily the parent who is responsible for organizing interactions by being sensitive to the infant's innate rhythms of attention, arousal, and affect (Kaye, 1982). Through the utilization of these rhythms, interaction between the parent and infant is facilitated, and conventions of communication are introduced (Murray & Trevarthen, 1986). Over time, however, the infant assumes increasing responsibility for the initiation, maintenance, and discontinuance of exchanges with parents (Tronick & Cohn, 1989). Thus, the reciprocity and turn-taking that characterize all social interactions first emerge in the context of the family, and are likely a result of the interaction of behavioural predispositions of the infant (e.g., temperament) and the systematic utilization of these behaviours by the caregiver.

If the caregiver demonstrates sensitivity to an infant's cues, and uses these cues to facilitate interactions, then the likelihood of a bond being formed between caregiver and infant is increased (Ainsworth, Blehar, Waters, & Wall, 1978; Isabella, 1993; Smith & Pederson, 1988). Several correlational studies have revealed that children who are securely attached are more independent (Sroufe, Fox, & Pancake, 1983), more flexible in problem-solving strategies (Arend, Gove, & Sroufe, 1979), more socially active (Waters, Wippman, & Sroufe, 1979), and appear to experience more positive and more protracted social interactions (Lieberman, 1977). In contrast, children who have insecure attachments appear to be less well-liked by peers and teachers, and are perceived as more aggressive by their classmates (Cohn, 1990). Thus, relationships established within the context of the family have a clear impact on later social and non-social skills.

Peer Relations in Childhood

Children's relations with peers can be distinguished from family relations by their nature and purpose (Hartup, 1980). Specifically, the equivalences in age, ability, and interests that characterize peer relations by necessity affect the nature of the interactions, and the consequence for those involved. Although the basic social skills used in later peer relations are established in early parent-child interactions, the quality of these later relations, and the child's resulting popularity, is a function of other factors as well.

Research incorporating measures of peer status has revealed consistent discrepancies between popular and unpopular children both in their behaviour and in non-behavioural characteristics. Some of the non-behavioural correlates of popularity that have been identified include birth order, physical attractiveness, athletic prowess, and physical and/or mental disabilities (Hartup, 1983). Although these traits are not considered to be the sole, or even most significant, determinants of peer status, it is important to recognize that variables other than social skills per se contribute to children's success in peer relations. That is, children's status in the peer group may be determined not only by what they do, but also by factors that predispose other children to evaluate them positively or negatively. Sadly, most of these attributes are beyond the control of the child.

Behavioural traits of popular and unpopular children have also been observed to differ, both within already established peer groups (Rubin, 1982), and in previously unassociated groups of children (Coie & Kupersmidt, 1983; Dodge, 1983; Putallz & Gottman, 1981). As might be predicted, popular children generally display cooperative and helpful behaviour, follow social rules, communicate effectively, and are friendly and supportive toward their peers. Although they are not significantly more outgoing than their peers, they are more receptive to the social approaches made by others. In contrast, rejected (i.e., unpopular) children often do not reciprocate the initiations of others, and do not themselves initiate interactions frequently. The interactions that are initiated are brief, and are often characterized by verbal and physical aggression. Frequently they display context-inappropriate behaviour.

Two other sociometric groups have been identified in the literature on peer status: Neglected children, who have low levels of both aggression and withdrawal and also tend to have limited social skills, and controversial children, whose disruptive behaviour is balanced by positive social skills (see Newcomb, Bukowski, & Pattee, 1993 for a more extensive review of behavioural correlates of peer status in childhood). However, most research on peer status in children with mental retardation has focused largely on the unidimensional popular/unpopular distinction.

A related and key social task for children is entering an established group of peers already engaged in an activity. Successful group entry and the resulting interaction may be crucial factors in long-term peer acceptance (Putallaz & Wasserman, 1990). Children who are successful at joining an established group display a specific sequence of behaviours, characterized by adaptation to the group's frame of reference, and by sensitivity to the group's response to their entry attempts (Dodge, Schlundt, Schocken, & Delugach, 1983). The sequence of behaviours that meet with the most positive response involve a steady progression from indirect to direct means of establishing contact with the group. Dodge et al. (1983) noted that children who were successful at entering the play of others began their attempt by waiting and hovering around the periphery of the group. This was followed by statements referring to the group's activity, or by mimicking the group's actions, and was accompanied by a gradual assimilation into the group proper. At no time did these children bring attention to themselves outside of the group's focus, or in any other way disrupt the group. Thus, the process of integrating themselves into an established group was gradual and subtle.

Friendships During Childhood

Status or popularity with a peer group is only one dimension of social competence. Research indicates that it is possible to have no friends but to be well-accepted by peers generally, or, conversely, to maintain specific friendships despite generally low peer group regard (Asher, Renshaw, & Geraci, 1980; Howes, 1988). Thus social acceptance and friendship do not refer to the same social phenomenon. While social acceptance refers to the degree to which an individual is liked or valued by a group of peers, friendship is a stable and reciprocal positive relationship between two individuals (Furman, 1982; Howes, 1988). Although the nature and sophistication of friendships change with development, the common themes underlying friendships at all ages are ego-reinforcement and mutual liking (Bigelow, 1977). Given that children with mental retardation are seldom rated as popular, and do not typically have a high degree of social acceptance (Bruininks, Rynders, & Gross, 1974), friendship is a potentially critical concept to review.

Price and Ladd (1986) have argued that friendships and broader peer relations may serve both overlapping and unique purposes. Specifically, they hypothesize that childhood friendships serve three major purposes: Friendships provide a context in which individuals acquire a variety of social competencies; they serve as resources for emotional support and security; and they function as precursors for later relationships. Therefore, children who maintain specific friendships in the absence of larger peer group acceptance may derive many benefits, some of which are comparable to those associated with high peer group regard, thereby ensuring later adjustment.

Similar to adult models of friendship (cf., Ginsberg, 1987), childhood friends are hypothesized to serve as a buffer for stressful life events, for example by providing a stable base, emotional support, and security for the child (Price & Ladd, 1986). The degree to which the presence of friends can mitigate stress and facilitate adjustment for children was elegantly demonstrated in a series of studies on the factors that affect successful transition from kindergarten to primary school (Ladd, 1990; Ladd & Price, 1987; Ladd, Price, & Hart, 1988). Only when new friendships were formed, or old friendships were maintained throughout the school year, was there a positive attitude toward school, coupled with improved school performance (cf., Berndt, 1990).

Friendships During Adolescence

It has been hypothesized that social groups assume greatest prominence during adolescence (Hartup, 1983; Steinberg, 1989). Adolescents in grades 7 through 12 reported, however, that the general importance of crowd affiliation in their lives decreased linearly with age (Brown, Lahr, & McClenhan, 1986). Among the reasons these students cited for membership in a peer group is that it provides both emotional and instrumental support during adolescence and increased opportunities for developing and maintaining friendships. Thus, it appears that friendships, and not the peer group per se, increase in importance during adolescence. Indeed, others have noted that both children and adolescents are more interested in their friends than in other peers (e.g., Ginsberg, Gottman, & Parker, 1986; Sharabany, Gershoni, & Hoffman, 1981).

Friendships among children and among adolescents share a number of features. These include how friendships are defined (e.g., by helpfulness; Berndt & Perry, 1986), the styles of interactions among friends (Newcomb & Brady, 1982), and the duration of these relationships (Berndt & Hoyle, 1985). However, friendships among adolescents differ from those among children in three primary ways. The first, intimacy and affection, is also one of the main functions served by adult friendships (Ginsberg, Gottman, & Parker, 1986). Adolescents perceive their relationships to be more intimate and supportive than do children — references to shared intimacy with a friend increase dramatically in early adolescence (Douvan & Adelson, 1966; Selman, 1981; Youniss, 1980). The second difference is that young adolescents consider trust and loyalty to be more important in relationships than do children. This may be reflected in the development of cliques, when the loyalty of a friend might be more important in the midst of larger peer groups. The third feature is that when opportunities for competition and sharing are mutually exclusive, young adolescents tend to compete less and share more with their friends than do younger children (Berndt, 1990). This transition occurs somewhere between middle childhood and early adolescence.

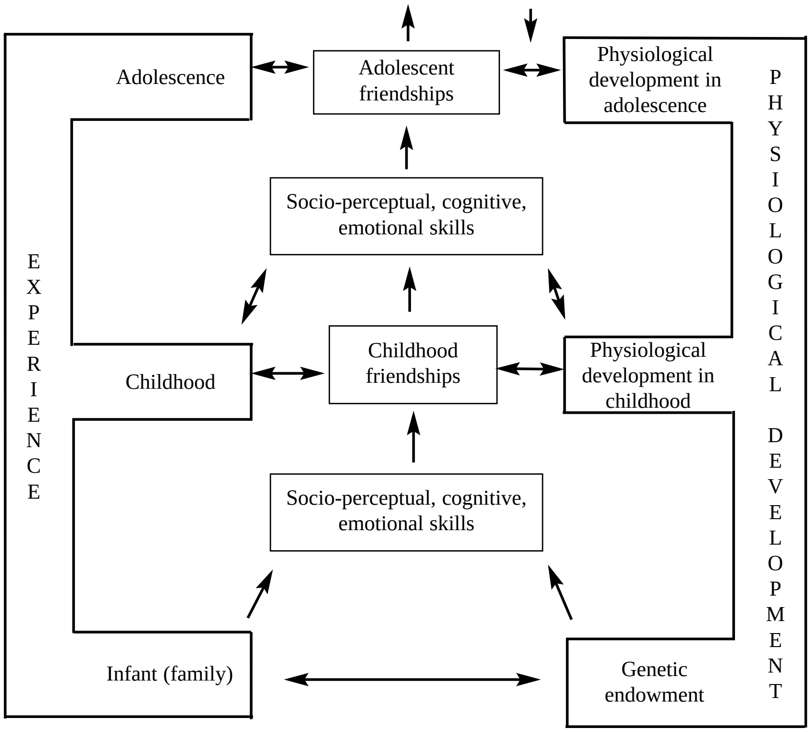
The growing importance of intimacy may be directly related to the decreasing importance of group membership reported by Brown et al. (1986). In addition, the focus of that intimacy shifts developmentally. Through to late childhood, family members are the most important companions of a child, followed by same sex peers (Burmester & Furman, 1987). Intimate friendships with peers of the same sex are evaluated as increasingly important and remain intense throughout the adolescent years. These relationships are particularly important for companionship, sharing of possessions, sharing of feelings and attitudes, and the development of trust (Sharabany, Gershoni, & Hofman, 1981). For heterosexual relationships, the development of intimacy between opposite sex friends typically begins in late preadolescence (Buhrmester & Furman, 1987; Sharabany et al., 1981), and increases until late high school years where it reaches the same level as same-sex friends. Further changes in intimacy and in the nature of friendships continue through young adulthood (e.g., see Fescher, 1981).

Models of Friendship

In order to integrate a number of themes which emerged from the foregoing review, we present two illustrations to use as heuristics for examining the literature on children with mental retardation. Figure 1 depicts the “process model” and Figure 2 presents the characteristics of friendship in children.

The process model, represented in Figure 1, attempts to incorporate the internal and external constraints on friendship formation in typical populations. Infants are assumed to enter the world with genetic traits that, to some extent, determine their potential for later competence. This can happen in two ways: (a) directly, by imposing limits on the ability to develop the requisite socio-perceptual, socio-cognitive, and socio-emotional skills, and (b) indirectly, by shaping early interactions within the family. For example, an infant’s temperament, or general sociability, will affect the quantity and quality of interactions with caregivers. These early experiences within the family may, in turn, influence the infant’s motivation for later social activities, and may also affect the development of rudimentary social skills with which to pursue them. The relation between early interactions and social skill development is dynamic, insofar as positive interactions will promote skill development that consequently enhances further interactions. Moreover, experiences in infancy not strictly in the social domain will impact on both skill development and family interactions. The experiences, genetic endowments, and resultant social skills of the infant work together to produce what we have called the precursors of friendships (see Fig. 2). Relationships are characterized by emergent reciprocity, turn-taking, and the formation of early attachments or bonds. These characteristics are assumed to be building blocks for friendships in later life, which is implicit in the nesting of friendship characteristics in Figure 2.

Figure 1. Process of Friendship Formation



Clearly, experiences as infants ultimately impact on experiences as children. In addition, physiological changes that come with age (e.g., increased mobility, height and strength, and attractiveness) may influence the likelihood of forming friendships. These two factors, together with the social, motivational, and psychological (e.g., self-esteem) attributes that have been fostered in infancy contribute to the formation of the child's first friendships. Again, a reciprocal relationship exists between children's experiences and their friendships: Changes in one will elicit changes in the other. Children’s friendships can typically be characterized by positive affect, prosocial behaviour, and shared interests and experiences (see Fig. 2). It is further suggested that the intimacy observed in childhood friendship is epiphenomenal; that is, it comes about as a result of shared activities, rather than of shared feelings. It is a passive by-product, rather than an active pursuit.

Figure 2. Characteristics of friendship in children

Adolescence (Shares Feelings and Ideas)
- Sensitivity to other’s needs
- Longevity
- Equality
- Active seeking of intimacy
- Loyalty and faithfulness
- Sharing of self (value, attitudes, experiences, possessions)

Childhood (Shared Activity)
- Among equals
- Like each other (positive effect)
- Helpful (prosocial behaviour)
- Spend time together
- Shared interests and experiences
- Intimacy emerging as a byproduct

Infancy (Precursor of friendship)
- Established within the family
- Reciprocity
- Turn taking
- Attachment/bonding

Given the increasing sophistication of peer interactions during childhood years, it follows that the skills underlying these relationships develop as well. One way in which this happens is through the typical development of the cognitive, perceptual and emotional systems. Clearly, however, this is not enough. At a minimum, social knowledge, social goals, and social norms must be acquired for peer interactions to be maintained and deepened. In addition, as with any skill, practice increases proficiency. Thus, it is likely that friendships in childhood contribute to the refinement of the skills that allowed their initial formation. The development of social skills is certain to influence children's experiences outside of their friendships, and indeed, may even affect their physical development (for example, by increasing the likelihood of participating in sports).

As indicated in Figure 2, adolescent relationships are typified by the active seeking of intimacy, and the sharing of feelings and ideas, among other characteristics. Three variables in particular are seen as contributing to the emergence of adolescent friendships (see Fig. 1). The first of these factors springs from the biological domain, the central feature of which is the onset of puberty with its biochemical, and hence physical and motivational, changes. Second, the experiences that adolescents carry with them no doubt affect the ease with which friendships are formed. Finally, the refinement of skills argued to underlie social competence plays a large role in the quality of close peer relations.

The models presented in Figures 1 and 2 provide a summary of some of the more salient themes derived from the literature on peer relations and friendship in typical populations. In the next sections these models will be used to help organize and evaluate the literature on individuals with mental retardation.

Family and Peer Relations in Children with Mental Retardation

As outlined in Figure 1, in the case for children without disabilities, early parent-child interactional patterns are claimed to contribute to later interactive styles, and indeed to form the basis of later social communication. It follows, then, that children with mental retardation who experience atypical parent-child relations may also experience some difficulty in establishing and maintaining effective peer interactions. Children with mental retardation have been hypothesized to be at higher risk for atypical parent-child relations due to a variety of factors, including difficult temperament qualities (e.g., Chess, 1970; Dosen, 1990), passivity, and more interactional directiveness by parents (Buckhalt, Rutherland, & Goldberg, 1978; Jones, 1977), perhaps in response to child characteristics.

Much of the research examining the social competence of children with mental retardation has focused on their social interactions and friendship development with peers both with and without mental retardation (see Buysse & Bailey, 1993 for a review). Guralnick and Weinhouse (1984) observed 48 mildly and moderately cognitively impaired 4-year-olds during free play on two separate occasions; once at the beginning and once at the end of the school year. Initially it appeared that the children with mental retardation engaged in peer interactions similar to those of children without disabilities. However, despite similarities to the features, organization, and developmental progression of peer interactions in typically developing children, closer observation revealed unusual deficits in peer-related social behaviour. Specifically, solitary and parallel play were the dominant forms of social participation, and a majority of the children failed to engage in sustained social interactions. Like unpopular children without disabilities, children with mental retardation were unable to turn simple two-unit initiation/response sequences into more elaborate social exchanges. These features remained stable throughout the entire school year. Comparisons with normative data indicated that the delays observed were beyond what would be expected on the basis of the children's developmental age alone (Guralnick & Weinhouse, 1984).

In a similar study, Guralnick and Groom (1985) observed children with mental retardation interacting in a free play situation to determine whether individual social behaviours found to enhance peer-related social competence in typical children were displayed. These behaviours, which rely on well-established socio-cognitive, socio-emotional, and socio-perceptual skills, include the ability to engage in sustained social play, to utilize peers as resources, to lead others, and to show affection. The role of language and behavioural characteristics in peer related social competence was also examined. As in the previous study, it was found that social interactions with other children were limited, with the majority of time spent playing alone or not at all. Although the children did engage in some social exchanges, many of the individual behaviours typically associated with peer-related social competence were absent. The authors hypothesized that the nature of the children's play behaviour at this level (i.e., nonverbal social acts) required minimal dependence on language. Accordingly, language may play an increasing role in peer related social competence only as children begin to engage in play behaviours which are more dependent on language skills. Unfortunately, direct comparisons were not obtained with a matched group of children without disabilities in either of these studies, making it necessary to interpret the findings with caution.

To follow-up on their previous findings, Guralnick and Groom (1987a) paired 4-year-old children who had mild delays with chronological-age matched (4-year-old) and mental-age matched (3-year-old) typical children, and with other 4-year-old children with mild delays. The purpose of this study was to explore the effect of companion status on the peer related social and play behaviours of children with mild mental retardation. When paired with other children with mild delays or with developmentally matched typical peers, the children with mental retardation displayed the same deficits as found in the previous two studies. In contrast, when these same children were paired with chronological-age matched peers who did not have disabilities, the quality of their social interactions increased substantially. There was a decrease in solitary play, greater involvement in group play, and the frequency of positive social interactions almost doubled. The specific individual social behaviours that were affected included attempting to gain the attention of peers, using peers as a resource, and increased initiation of peer behaviour. The authors hypothesized that the observed differences may have been due to the fact that the older typical children were able to take a more active role in organizing and generating productive social interactions, whereas the younger typical children lacked these skills.

Guralnick and Groom (1987b) next created several playgroups composed of previously unacquainted 3- and 4-year-old typical children and 4-year-old children with mild delays; peer-related social and play interactions of the children were observed during a free play period. Peer sociometric ratings were obtained at the completion of each playgroup. Many of the deficits in peer-related social interactions that had been observed in the previous studies were also apparent in the mainstreamed playgroups. That is, the children with mild delays engaged in more solitary play, and were the least socially interactive group of children. They were also the children who were used least often as resources by other children, and were used infrequently as models. The children with mild delays were the only group to show an overall decline in the ability to obtain positive outcomes to their social initiations over time. It was clear from both the observational measures and sociometric ratings that the children with mild delays were the least preferred play partners of both the 3- and 4-year old typical children.

Others (e.g., Asch, 1989) have also reported that simply placing children with mental retardation and typical children together had little effect on the quality or quantity of their interactions. Jenkins, Odom, and Speltz (1989) found that preschoolers with mild to moderate mental retardation actually spent more time playing alone in an integrated classroom, than when in a classroom composed of peers with mental retardation. Only when a play program encouraging social interaction was implemented did the children with mental retardation engage in a higher proportion of interactive play, regardless of the classroom setting. Moreover, outcome measures indicated that by the end of the year all children with disabilities involved in the social interaction play program had improved language scores, and that those children who were in the integrated classrooms were rated by their teachers as being significantly more socially competent.

Sometimes, however, even intervention is not enough to promote interactions between typical children and their peers with mental retardation. A one-time intervention designed to increase grade school children’s awareness of their disabled peers’ need for friends failed to foster social interaction (Fischer Fritz, 1990). Although the children with mental retardation reportedly approached, observed, and attempted interactions with their typical peers, these overtures were rarely reciprocated. Similarly, interactions with children with mental retardation were only infrequently initiated by typical peers. The author suggests that the majority of typical peers either fail to acknowledge social overtures made by someone who is different from them, or fail to consider these children as their social peers.

Taken together, these research findings indicate that children with mild developmental delays have social deficits in dyadic as well as group play interactions with typical children, and that these deficits are beyond that which would be expected based on developmental level alone. Differences have been identified both in infant-parent interactions and in peer interactions at preschool ages. As indicated in our model (see Fig. 1) these are not likely independent outcomes. The initial infant-parent interaction pattern is at least partly a result of the natural endowments of the infant; this early pattern will then have a profound effect on later interactional style. This suggestion has been born out by the observation that older typical children can elicit positive and prolonged social interactions from children with mental retardation. Thus, just as caregivers orchestrated early family interactions, older, more socially skilled children must lead the way for successful peer relations. We may speculate, then, that many children with mental retardation either do not have, or do not use, the skills required for sustaining social interaction. This interactional style may have an impact on, among other things, the ability to develop friendships.

Friendships in Children with Mental Retardation

Although the role of friendships for children with mental retardation is unclear, there is evidence to suggest that friendships serve similar functions as for children without disabilities (Gold, 1985; Guralnick & Groom, 1988).

Guralnick & Groom (1988) examined the behaviourally defined friendship patterns of 4-year-old children with mental retardation in a mainstream play group consisting of 3- and 4-year-old typical children. Observations of the social behaviours of the children were used to index friendship. The authors were specifically interested in whether children with mental retardation were able to establish unilateral and reciprocal friendships with typical peers. A unilateral friendship occurred if a child with mental retardation directed 33% of his/her interactions to a specific companion. A reciprocal relationship was defined when a child with mental retardation directed 33% of his/her interactions to a specific companion, who in turn directed 33% of his/her interactions to the target child. Children with mental retardation showed a clear preference for the chronological age matched typical children in establishing both unilateral and reciprocal friendships. The results indicated that although the children with mental retardation were able to establish the same number of unilateral friendships as the two typical groups of children, only two of the eleven children with mental retardation met the reciprocal friendship criterion. Thus, according to these measures, the friendships of children with mental retardation were rarely reciprocated.

However, more qualitative explorations of the development of friendships between children with and without mental retardation have indicated that children with mental retardation do develop close reciprocal relationships. Gold (1985) found that the children in her study, ranging in age from 6 to 12 years, had developed a variety of friendships, including close peer friendships. These close friendships possessed a quality of “mutuality” (p. 17), suggesting that both children appeared to acknowledge and seek the friendship, and found it mutually beneficial. Other qualities of the friendships included humor, affection, understanding, and concern. Efforts on the part of significant adults such as teachers and parents to facilitate friendships were an important component of the process of developing friendships between children with mental retardation and typical peers (Gold, 1985; Gottlieb & Leyser, 1981). This finding is supported by others, such as Strully and Strully (1993), who provide a personal account of friendship between their daughter, who has mental retardation, and typical peers. They describe their daughter’s friendships as being beneficial to both children in the relationship, and state that friendships are critical to the happiness and well-being of their daughter. They also indicate that their own efforts in facilitating opportunities for these friendships were an important factor in friendships developing (see also Hamre-Nietupski, 1993). Qualitative studies, therefore, suggest that children with mental retardation are capable of establishing friendships with typical peers. However, it is unclear whether these friendships could be established without the active facilitation of caregivers.

Clearly, more research is needed to determine the nature and extent of friendships among children with mental retardation. To date, it appears that reciprocal friendships are not readily established by children with mental retardation without the direct intervention of others. For example, in unstructured settings, it is typically older typical children who elicit positive social behaviour from children with mental retardation. This trend continues into adulthood (Barber & Hupp, 1993). With sufficient effort, close relationships that provide many of the benefits associated with friendship can be established and maintained. Without such help, however, the outcome is less optimistic. When left alone among peers, children with mental retardation spend the majority of their time playing alone or not at all; their social interactions are infrequent and brief. In the context of our model, it might be predicted that the failure to make friends will have profound consequences on other life experiences (this issue will be further discussed, below).

Both peer acceptance and friendship development play an important role in the social and emotional well-being of children. Deleterious effects associated with both general peer rejection and failure to establish individual friendships have been identified. It is not clear whether success in one of these social domains can fully protect an individual from the negative effects of failure in the other. Given that children with mental retardation have difficulty establishing and maintaining social relations, continued efforts are needed to enhance both social skills and acceptance among peers. Otherwise there is a likelihood of ongoing difficulties with social relations and a subsequent risk to later adjustment. In addition, systemic barriers to friendship formation need to be considered (Amado, 1993).

Mental Retardation, Peer Relations and Later Adjustment

Adjustment difficulties and an increased incidence of psychopathology have been well-documented in people with developmental disabilities. Prevalence rates from studies with a variety of sample sizes vary considerably (Eaton & Menolascino, 1982; Groden, Domingue, Pueschel, & Deignan, 1982; Menolascino, 1968; Philips & Williams, 1975; Rutter, Graham et al., 1970; Rutter, Tizard, & Whitmore, 1970). Most studies based on samples of children with developmental disabilities who live with families and in communities suggest prevalence rates ranging from 14% to 40%, depending on the definitions of psychiatric disorder and mental retardation (Russell, 1985). Children with mental retardation appear to experience the same kinds of psychological disorders as those in children without disabilities (Chess & Hassibi, 1970; Eaton & Menolascino, 1982; Philips & Williams, 1975; Reid, 1980; Rutter, Graham et al., 1970). The full range of psychoses, mood, personality, adjustment, and behaviour disorders, are evident among individuals with mental retardation (Menolascino, 1990), although depression is diagnosed more frequently among children and youth with mild mental retardation (Menolascino, 1990).

Causal variables associated with the relation between mental retardation and psychological disturbances are difficult to study because of the heterogeneity of etiologies associated with both conditions (Corbett, 1977; Menolascino, 1977; Russell, 1985). Traditionally, the most common approaches to understanding the mechanisms underlying this relation have been unidimensional in nature: Organic causes such as brain damage (Chess, 1977) as well as environmental and family stressors (Chess, 1970; Nihira, Meyers, & Mink, 1980; Richardson, Koller, & Katz, 1985) have been proposed.

More recently, models have been proposed which attempt to account for the dynamic interaction between multiple intrinsic and extrinsic factors underlying the association between mental retardation and psychological disturbances (Cicchetti, 1990; Cicchetti & Beeghly, 1990; Dosen, 1990; Dosen & Geilen, 1990; McGee & Menolascino, 1990; Menolascino, 1977). These transactional approaches emphasize the vulnerability of children with mental retardation and the importance of children's interactions with caregivers.

In an attempt to understand the mechanisms underlying the relationship between mental retardation and psychological disorder, research and theory have focused on the importance of relationships with caregivers for the prevention of dysfunctional disorders in children with developmental disabilities. Most research has focused specifically on parent-child relationships; well-developed hypotheses and research linking lack of peer relationships to psychopathology among children with mental retardation are notably absent. However, the potential importance of friendships as a protective factor for children with mental retardation cannot be ignored. Friendships are thought to provide emotional support and security (Ladd, 1990; Price & Ladd, 1986) which help to mitigate the stress of various life events that would otherwise put the child at risk for developing a psychological disorder. Although early parent-child interactions set the stage for later peer relationships, friendships among same-age children are argued to make a unique contribution to children's well-being.

An absence of friends and of peer acceptance in children with mental retardation, then, may leave them vulnerable to a variety of adjustment disorders. In our model (Fig. 1), three variables are identified as significant contributors to friendship formation. When the biological/physical contributions, the prior experiences of the individual, and the refinement of existing social skills are emerging in a mutually facilitative fashion, the individual is likely to have developed important friendships which contribute to overall mental health. If either the physical or experiential contributors become dysfunctional (e.g., through repeated hospitalizations), the existence of supportive friendships may help moderate the impact of these contributors. If, however, existing friendships are not available (e.g., as a result of long-term cumulative impairments in the physical and experiential domains), then the risk of adjustment problems may be increased. This view may help to explain the elevated prevalence of depression and other adjustment disorders among people with mental retardation.

Research to date reveals that adults with mild and moderate mental retardation who have been diagnosed as depressed exhibit greater deficits in social skills than those not labelled as depressed (Laman & Reiss, 1987; Matson, 1982; Reiss & Benson, 1985). It is, of course, not possible to determine if the lack of social skills causes the depression or if deficient social behaviours may be a result of the depression. Nonetheless, insight into the nature of peer relations and friendships in children with developmental disabilities could further our understanding of the relationship between social development and dual diagnosis. A better understanding of the dynamics underlying social competence would make a significant contribution to the area of intervention strategies, a matter to which we now turn.

Intervention and Instruction

Many interventions aimed at social skills training have been used with children with mental retardation. These interventions have typically involved some combination of direct instruction, modelling, role play, social reinforcement, and practice (Bellack & Hersen, 1979). The work of Strain and his colleagues (Strain & Kerr, 1981; Strain, Odom, & McConnell, 1984) has indicated that positive social interactions of children with developmental disabilities can be increased using both adult- and peer-mediated interventions. These interventions primarily rely on promoting and social and primary reinforcement as means of increasing social interaction. Specific behaviours that have been targeted include social play, sharing, appropriate displays of affection, and giving assistance. Although children showed significant improvement during treatment, the acquired skills frequently were not maintained and did not generalize beyond the treatment environment.

In a review of intervention strategies aimed at overcoming the rejection and isolation of cognitively impaired children, Gottlieb and Leyser (1981) described a strategy known as sociometric grouping. This technique involved rearranging the classroom based on the results of sociometric testing so that low-status children were in closer proximity to high-status children. The authors reported that despite the initial increase in peer status, such changes were often not maintained at follow-up. Furthermore, although children's sociometric status may change, their behaviour may not. Clearly this would continue to affect their success at forming positive social relationships. Efforts at changing behaviour through role playing have not been found to be successful, although reinforcement, coaching, and modelling have shown some success (Gottlieb & Leyser, 1981).

Facilitating individual friendships is another possible goal of intervention. Stain back and Stain back (1987) have identified some skills necessary for the development of friendships. These include the ability to learn about another person and compare interests, to take the perspective of others, to share and be supportive, to be trustworthy and loyal, and to resolve conflicts. Various methods of teaching these skills were discussed by Stain back and Stain back, and included systematic reinforcement, role playing, modelling and coaching. However, their theoretical analysis has yet to be empirically validated.

Conclusions and Directions for Future Research

An emergent theme of this paper has been that limited peer interactional skills and difficulty developing lasting friendships may be directly associated with the development of psychological disorders among children with mental retardation, as well as in the wider population. Several directions for future research follow from this perspective:

1. Research linking family functioning, socialization and quality of caregiver-child interactions with the development of peer relational skills among children with mental retardation needs to be conducted. Uncovering family environment factors related to the acquisition of adaptive social skills will have direct intervention implications. Since the presence of a child with mental retardation in a family can present special parenting challenges, factors that can be shown to enhance or facilitate the social development of children with mental retardation can guide future intervention programs.
2. Examination of the relationship between the inability to establish friendships and psychological disorder among children with mental

retardation is required. It is unlikely that all children with mental retardation exhibit social skills difficulties and a failure to develop friends. Further, of the children who do lack these skills, what percentage subsequently develop, or currently exhibit psychological disorder; conversely, what are the protective factors that make some children more resilient to psychopathology? Optimally, this question should be examined within a longitudinal framework in order to capture the developmental processes that lead to the emergence of psychological disorder. Other potential moderating factors of the relationship should also be investigated such as age of the child (preschool, middle childhood, adolescence, adulthood), gender, and family variables.

3. The precise nature of the cognitive and language processing deficits and the emotional and personality differences among children with mental retardation that are associated with poor peer relational skills requires exploration. Although a variety of deficits have been proposed to be related to the unsuccessful development of peer relationships, empirical demonstrations of significant concrete linkages have yet to be established. For example, Cicchetti (1991) suggests that delays in the acquisition and use of emotional language by children with Down syndrome could lead to difficulties in emotion regulation. Whether these deficits are related to poor peer relational skills remains unclear.

4. Research in the area of mental retardation has not adequately addressed differences in the development of organic versus familial mental retardation. The similarities and differences in the development of these two groups of children, initially identified by Ziegler (1969) and Ziegler and Bala (1982), should be studied. Although recent research has demonstrated that there may be more similarities in some domains than once thought (Cicchetti & Beeghly, 1990), a number of differences remain, for example, in family functioning (Crnic, Friedrich, & Greenberg, 1983). It is precisely these types of differences that may be significant for later social and personality adjustment.

5. Finally, the importance of using comparison groups of typically developing children when studying atypical populations should be underscored. The patterns of relations among systems of development in typical and atypical groups cannot be assumed to be identical (Cicchetti & Beeghly, 1990). For example, Crnic and Greenberg (1987) have discovered that the relations among family factors and

maternal and child factors were different among families with and without high risk infants Differences in patterns of relationships between children with and without mental retardation suggest different developmental pathways. The uncovering of key variables that influence social behaviour in children with mental retardation is essential to the development of effective intervention strategies.

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Training Task Assignments and Aberrant Behaviour of Persons With Developmental Disabilities

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Abstract

We monitored the frequency of aberrant behaviour of 13 persons with developmental disabilities in their respective prevocational training programs. During observation sessions, the direct-care staff unknowingly assigned clients to training tasks that were sometimes matched and sometimes mismatched to their ability levels, according to the Assessment of Basic Learning Abilities (ABLA) test. Before staff training and prompting about the ABLA test, 83% of the tasks presented by staff across the three classrooms were mismatched to the clients' ABLA test levels, and 9 of the 13 clients showed high frequencies of aberrant behaviour. Teaching the staff about the ABLA test via a self-instructional manual, and prompting them to apply it, led to a large increase in the percentage of matched tasks that staff presented to clients, and a decrease in aberrant behaviour.

Training tasks for persons with developmental disabilities are frequently selected by direct-care staff. However, DeWiele and Martin (1996) observed that direct-care staff at a residential training facility for persons with developmental disabilities frequently did not suitably match the learning abilities of clients to the difficulty level of training tasks, according to the Assessment of Basic Learning Abilities (ABLA) test. In another study, using an alternating-treatments design with three participants, Vause, Martin, and Yu (1999) demonstrated that tasks that were mismatched to a client's ABLA test level resulted in more aberrant behaviours than did tasks that were matched to a client's ABLA test level. The present study examined this latter finding with a larger sample and in three pre-vocational training programs.

An important finding related to the ABLA test is that a failure to pass a level on the ABLA test will result in tasks at that level being extremely resistant to training using standard reinforcement and prompting procedures (Meyerson, 1977; Stubbings & Martin, 1995; Wacker, Steil, & Greenbaum, 1983; Witt & Wacker, 1981; Yu & Martin, 1986). A cost effectiveness analysis suggested that training, using standard reinforcement and prompting procedures, on tasks above a client's ABLA level can result in a great deal of unproductive training time (Stubbings & Martin, 1995). Moreover, there may be costs over and above unproductive training time when there is a mismatch between the ABLA level of a client and the ABLA difficulty of training tasks. Using an alternating-treatments design, Vause et al. (1999) demonstrated, during structured one-on-one training sessions with three participants that tasks above clients' ABLA levels resulted in more aberrant behaviour than matched tasks. This finding is consistent with other studies (e.g., Weeks & Gaylord-Ross, 1981) that have observed higher rates of problem behaviours on difficult versus easy tasks. However, Vause et al. (1999) also observed more aberrant behaviour on tasks below the clients' ABLA levels than on matched tasks. Moreover, Vause et al. observed that aberrant behaviours generalized to a second setting immediately after each training session.

The present study systematically replicated the Vause et al. (1999) study with a larger participant sample, and in three pre-vocational training programs. Moreover, this study examined whether instructor training and prompting about use of the ABLA test would increase the percentage of tasks, presented by the instructors, that were matched to the clients' ABLA levels.

Method

Setting and Participants

Observations occurred in three adult training classrooms at the St. Amant Centre, a residential and community training facility for persons with developmental disabilities. A typical classroom contained several tables, with training tasks set up at each table. In these classrooms, training on pre-vocational tasks was provided. These classrooms were selected because residents were at a wide range of ABLA levels, and staff indicated that residents frequently displayed aberrant behaviour.

Persons with developmental disabilities. In each of the three classrooms, there were four to twelve clients present at any given time. Six clients from each of the three classrooms were initially selected to participate, for a total of 18. These clients were selected because they were scheduled to be present in the classrooms for the longest period of time per day, as compared to other clients who only attended on a part-time basis. Upon completion of the study, five clients were excluded from the results because less than three data points were available. Three data points are generally considered the minimum to establish a trend (Hersen & Barlow, 1976). The age, functioning level, and ABLA level of the thirteen clients are presented in Table 1.

Direct-care staff. One instructor and one or two aides were typically present in the classrooms during observation sessions. One instructor in each of the three settings was trained on the ABLA test near the middle of the study. The instructors had been working with persons with developmental disabilities from 4 to 13 years, with an average of six and a half years. All three instructors were female, and had completed a Grade 12 education, with two of the instructors possessing some post-secondary education. The aides were male and female, and their education ranged from Grade 10 to some post-secondary education. The instructor in each classroom had the primary responsibility for selecting and sequencing training tasks for the participants.

Assessment Prior To Data Collection

ABLA Assessments. Prior to observation sessions, the ABLA test was administered to all participants as described by Kerr, Meyerson, and Flora (1977; see Martin & Yu, 2000, for a description of the procedures). The highest passed level for each participant is shown in Table 1.

Table 1. Characteristics of Participants

Participant	*Age*	*Functioning Level Highest*	*ABLS Level Passed*
1	24	severe	2
2	24	severe	3
3	28	severe	4
4	42	severe	3
5	33	severe	4
6	26	moderate	3
7	26	severe	4
8	29	moderate	6
9	42	moderate	4
10	26	severe	3
11	28	severe	3
12	25	moderate	4
13	32	severe	4

Classification of training tasks. As described by Stubbings and Martin (1995), training tasks presented to participants were analyzed according to the highest ABLA level required to perform each task. As described in Martin and Yu (2000), the ABLA levels include a simple imitation (level 1), a two-choice position discrimination (level 2), a two-choice visual discrimination (level 3), a two-choice visual identity match-to-sample discrimination (level 4), a two-choice auditory discrimination (level 5), and a two-choice auditory-visual combined discrimination (level 6). A sample of the training tasks presented in the three classrooms is described in Table 2. Across classrooms, training tasks presented ranged in difficulty from ABLA Level 2 to ABLA Level 4. Most of the training tasks observed for the study were those that were assigned by staff in the adult program settings. For participant 8, however, because staff did not assign to him tasks at his ABLA level, a novel task was sometimes assigned to him.

Table 2. Examples of Training Tasks Used in Study

Task Description	*Highest ABLA Level Discrimination Required*
Stuffing envelopes: A stack of envelopes and a stack of papers are placed, in a fixed position, in front of the client. The client is required to place a piece of paper in an envelope.	Level 2, Position
Tee Filling: A tee board is placed in front of the client. The client is required to place colored tees in the tee board, while visually discriminating which tee holes are vacant, which changes as each hole is filled.	Level 3, Visual
Sorting Cutlery: A client is presented with a cutlery tray that contains three compartments. A fork, a knife, or spoon is placed in one of the three compartments as samples. The client is required to place a utensil in the appropriate compartment (based on the sample utensil).	Level 4, Visual identity Match-to-Sample

Identification of aberrant behaviours. Aberrant behaviours of clients were observed in the classrooms during three sessions, each of approximately 20 minutes duration, prior to formal data collection, and a list of aberrant behaviours for each participant was then composed. During the first part of the study (before instructor training), several other behaviours were observed and added to the list. The set of aberrant behaviours for each participant remained unchanged subsequent to instructor training. Definitions of aberrant behaviours were modeled after definitions of such behaviours contained in the *Aberrant Behavior Checklist* (ABC) (Aman & Singh, 1986). Aberrant behaviour across clients included, among other behaviours, irritability, lethargy, stereotypy, hyperactivity, and inappropriate speech, which are listed as subscales in the ABC. Examples of definitions of aberrant behaviour specified in the ABC, and used in this study, included: (a) repetitive speech which was defined as "vocalizes certain words, phrases, or sentences repeatedly"; and (b) repetitive hand, body, or head movements which were defined as "self-stimulatory behaviour with no apparent desirable consequences." In some instances, for recording purposes, definitions were made more specific. For example, a type of repetitive hand movement for one participant was defined as "repetitive twirling of fingers beside or in front of face." Definitions of some of the aberrant behaviours displayed by many of the participants are provided in Table 3.

Table 3. Definitions of Common Aberrant Behaviours

Repetitive speech	Vocal stereotypy; vocalized nonsense syllables repeatedly
Rocking	Any instance of rocking back and forth while in an upright position
Restless, Unable to sit still	Continually standing up, sitting down, moving
Waving objects	Any instance of waving task materials in front of face or beside ears
Banging or tapping	Any instance of banging or tapping with hands on desk or with feet on floor

Procedures

Research design. Prior to the study, as indicated previously, the researchers determined the highest ABLA level passed by each client, and the highest ABLA level of each task (typically presented to the clients) that was necessary to readily perform each task. During the first part of the study, observers recorded the ABLA level of training tasks presented by staff to clients, and monitored aberrant behaviour while clients were working on those tasks. Then, during the second part of the study, staff received training on the ABLA test, and were prompted to match the ABLA level of clients to the ABLA difficulty level of training tasks. To examine whether there was an increase in the presentation of matched tasks after training and prompting about the ABLA test, the study used an A-B design replicated across three staff members in three settings.

Observation sessions. One instructor and one or two aides were present in the classrooms during observation sessions. Across classrooms, observation sessions were conducted one to four times per day, and during an average of three and a half days per week. On average, 3 participants (range of 1 to 4) from any given classroom were present during an observation session. The total number of observation sessions per participant ranged from 8 to 27, with a mean of 17. On average, 10 observation sessions per participant occurred before staff training and prompting on the ABLA test, and 7 observation sessions occurred after staff training.

The study used a combined partial interval and time-sampling recording system for observation (Martin & Pear, 1999). The observers monitored the behaviour of one client for 10 seconds, followed by monitoring the behaviour of the next client for 10 seconds, and so on until all participants present in the classroom had been observed. This method of sampling was repeated five times during a session. Within each 10-sec observation interval observers recorded the task that the client performed and whether any of the aberrant behaviours, previously specified for that individual, occurred or did not occur. Stated differently, an observer had a list of several aberrant behaviours that were typically displayed by a participant. If any one of those behaviours occurred during a 10-sec observation interval, a mark was made on the recording sheet. Thus, specific individual behaviours were not recorded separately. Rather, records indicated whether any aberrant behaviour of a participant occurred or did not occur. During all observations, task materials were readily available to the participant. During circumstances where task materials were not readily available for a participant (e.g., no cutlery left to sort), that participant was not observed.

Training procedure with front-line staff. A self-instructional manual developed by DeWiele and Martin (1998) was used to train the instructors how to administer the ABLA test (the details of the training and the results are described in DeWiele, Martin, & Garinger, 2000). The manual contained detailed guidelines on how to administer each ABLA level, and several study exercises corresponding to each level. In addition, it contained a section on how to appropriately classify training tasks according to the highest ABLA level needed to perform the tasks.

The instructors participated in four training sessions, which included studying the self-instructional manual until they meet a preset mastery score of at least 90% on three exams. Upon completion of the exams, staff were also required to test two or three residents on the ABLA test. ABLA classification of the four participants was scored by the tester as well as an independent observer who was familiar with the ABLA test. Agreement of ABLA classification was 100% across all residents tested.

Immediately following training on the ABLA test, each instructor was shown a graph of the data up to that point concerning the frequency of matched and mismatched tasks, and the occurrence of aberrant behaviour within her classroom. Instructors were then prompted to use the ABLA test in order to match the assignment of training tasks to the learning abilities of clients. The instructors were provided with charts containing the ABLA skill levels of participants in their classroom, and examples of training tasks that matched the skill levels of the participants. Subsequent to the feedback session, instructors received prompting from observers, approximately three times each, concerning the selection of matched tasks. Prompting consisted of providing general comments as to how a task could be modified to fit a specific ABLA level.

Reliability assessments. Interobserver reliability (IOR) checks were conducted during the ABLA testing sessions. During IOR checks, the tester and an observer independently recorded the participants' responses on each trial. An agreement was scored if the tester and the observer recorded the same response. A disagreement was scored if the tester and the observer recorded different responses. IOR scores were computed by dividing the number of agreements by the number of agreements plus disagreements, and then multiplying by 100%. IOR scores for ABLA testing were conducted for 7 participants, and scores ranged from 85% to 100%, with a mean of 93%.

IOR checks were also conducted during observation sessions in the classrooms. Two observers independently recorded the aberrant behaviour of a participant. An interval was scored as an agreement if both observers recorded that an aberrant behaviour (any one of several for a participant) occurred, or did not occur on a given trial. An interval was a disagreement if the observers did not agree that a behaviour occurred. IOR scores were calculated as described for ABLA testing. IOR checks for aberrant behaviour were conducted during 71% of observations sessions, and scores, across participants, ranged from 40% to 100%, with a mean of 95%. The means and ranges of IOR checks for each participant are presented in Table 4.

Table 4. IOR's for Aberrant Behaviour

Participant	*Mean IOR%*	*Range IOR%*	*Participant*	*Mean IOR%*	*Range IOR%*
1	99	80-100	8	96	80-100
2	100	100-100	9	99	80-100
3	98	80-100	10	96	80-100
4	91	75-100	11	97	60-100
5	96	60-100	12	100	100-100
6	98	80-100	13	82	40-100
7	87	60-100			

In addition, IOR checks were conducted for the classification of training tasks. Two observers independently recorded the highest ABLA level required for a participant to perform training tasks provided by instructors to participants. IOR scores for ABLA classification of tasks were calculated as described for ABLA testing, and ranged from 95% to 100%, with a mean of 98%.

Results

Figure 1 shows the mean percentage of aberrant behaviour, across the entire study, for each participant when tasks were matched and mismatched to the participants' ABLA levels. Out of 13 participants, 9 participants (S1 through S9) confirmed the prediction that training tasks mismatched to a clients' ABLA level would result in more aberrant behaviour than matched tasks. An analysis of mismatched tasks across all sessions showed that 87% of the tasks were below the participants' ABLA levels.

A one-tailed t-test for dependent samples was used to compare the mean percentage of aberrant behaviour for matched and mismatched tasks of the 13 participants across all sessions. For nine of the thirteen participants, the presentation of matched tasks resulted in less aberrant behaviour (*M*=37%, *SD*=25) than mismatched tasks (*M*=47%, *SD*=25), but the results did not quite reach significance, *t*(12)=1.69, *p*=.058. This may have been due to the small sample size.

Figure 2 shows the mean percentage of matched tasks and the mean percentage of aberrant behaviour across the three classrooms before and after instructor training and prompting on the ABLA test. Before instructor training and prompting, the percentages of matched tasks presented to participants across classrooms averaged 16%, 32%, and 12%, respectively. Subsequent to instructor training and prompting, the percentages of matched tasks presented to participants across classrooms averaged 77%, 79%, and 79%, respectively. As expected, across the three classrooms, mean aberrant behaviour decreased from 47 to 30 percentage points (a 36% reduction), from 45 to 40 percentage points (a 11% reduction), and from 57 to 45 percentage points (a 21% reduction) respectively. This pattern occurred for 9 of the 13 participants.

A one-tailed test for dependent samples was used to compare the mean percentage of aberrant behaviour across 13 participants before and after staff training on the ABLA test. The percentage of aberrant behaviour before training (*M*=47%, SD=23) was more than after training (*M*=37%, *SD*=28), but did not reach significance, *t*(12)=1.41, *p*=.09. The failure to reach significance may have been due to the limited sample size, or perhaps due to the small number of observation sessions (an average of 7 sessions per participant) that occurred following staff training and prompting on the ABLA test.

Discussion

When studies conducted by Ediger, Holborn, and Vermette (1996) and Vause et al. (1999) are combined with the present results, training tasks matched to a client's ABLA level resulted in considerably fewer aberrant behaviours than training tasks mismatched to a client's ABLA level for 15 of 19 participants. These results support previous research (e.g., Weeks & Gaylord-Ross, 1981) that demonstrated higher rates of problem behaviours of persons with developmental disabilities on difficult versus easy tasks. The results of the current study also add to the literature in three ways. First, they confirm, with a larger sample, the finding of Vause et al. that easy tasks as well as difficult tasks are correlated with higher frequencies of aberrant behaviours than are tasks that are matched to a client's ABLA level. Second, this finding was replicated in group training settings, despite the presence of uncontrollable factors. For example, the number of clients and teachers present in classrooms often varied from one session to the next. This likely had an effect on such variables as reinforcement, physical guidance, and verbal prompting provided to the participants during task presentation. However, despite these factors, consistent findings concerning aberrant behaviour emerged. Third, this study provides further support for the use of the ABLA test as a precise tool for measuring and matching the learning abilities of clients to the difficulty levels of training tasks, as opposed to subjectively judging tasks as "easy" or "difficult."

Figure 1. *Mean percentage of aberrant behaviour across the entire study when tasks were matched and mismatched to the participants' ABLA levels*

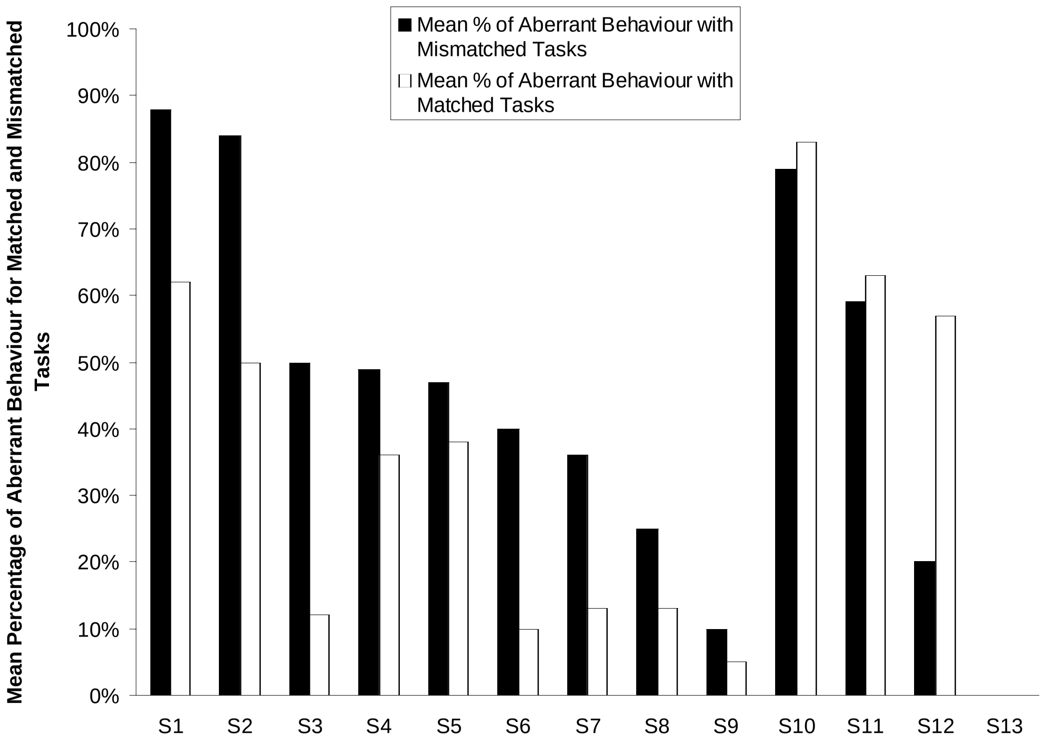
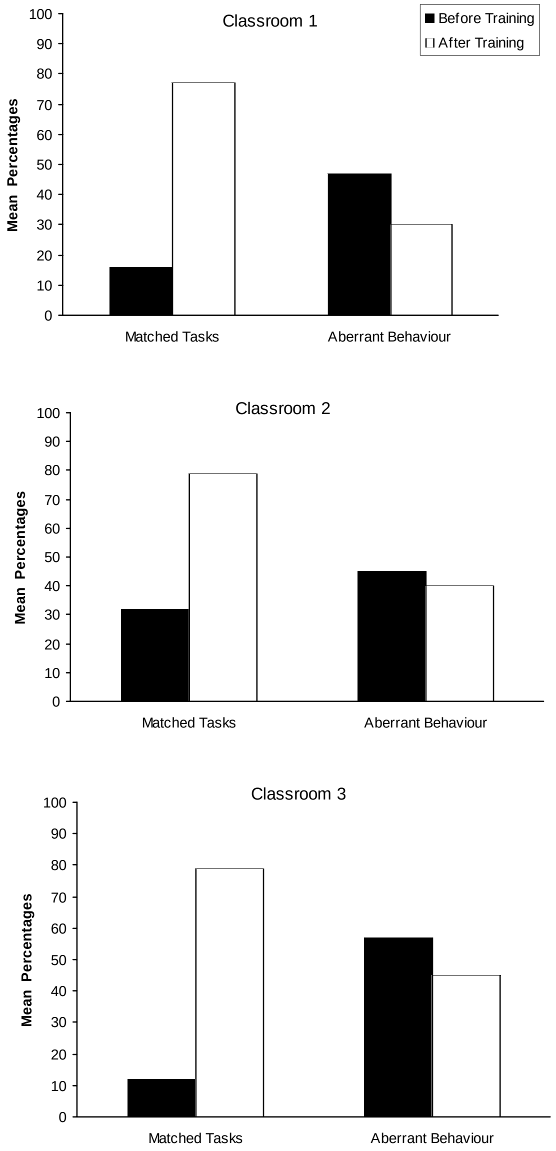


Figure 2. Mean percentage of matched tasks and aberrant behaviour for each of the three classrooms before and after training on the ABLA test.



A second purpose of the study was to evaluate whether instructor training and prompting about the ABLA test would increase the presentation of matched tasks. Before the instructors learned about the ABLA test, there was a frequent mismatch between a client's ability level, and the difficulty level of the training task. Only 17% of training tasks presented to participants prior to instructor training and prompting on the ABLA test were matched to participants' ABLA levels, and the large majority of assigned training tasks were below participants' ABLA levels. However, subsequent to instructor training, 76% of training tasks presented to participants were matched to participants' ABLA levels, and aberrant behaviour decreased for 9 of the 13 participants.

Several limitations of the present study need to be noted. First, as illustrated by a perusal of Table 3, the majority of aberrant behaviours were relatively mild in nature. Nevertheless, a high frequency of such behaviours, especially in group education settings, can be highly disruptive to effective training. Second, the improved matching by staff of participants' ABLA levels to the ABLA difficulty level of training tasks occurred following a combination of staff training via a self-instructional manual and subsequent prompting to apply the ABLA test. It would have been desirable to separate the effects of the two variables. Third, although large effects were obtained in improved matching by staff following training, and although post-training results were replicated in all three classrooms, the AB design is weak on internal validity. Future research should compare, using a stronger design, the relative effects of the self-instructional manual and staff prompting as strategies to influence direct-care staff to use the ABLA test.

The results of this study have implications for curriculum development for persons with severe developmental disabilities. Horner, Sprague, and Flannery (1993) suggested that, in building functional curricula for students with severe intellectual disabilities and severe problem behaviours, consideration should be given to removing discriminative stimuli for problem behaviour. The present study confirms the finding of Vause et al. (1999) that tasks that are above or below a client's ABLA level are likely to include stimuli that are discriminative for problem behaviour. In their discussion of strategies for modifying instructional stimuli that are discriminative for problem behaviour, Horner et al. (1993) cited several studies that suggest that, when problem behaviours are associated with difficult tasks, a plausible curricular decision may be to use an "interspersal" strategy. With this approach, staff would intersperse training trials using known, easy tasks with training trials on more difficult tasks. Horner et al. suggest that this strategy may lead to better learning on the difficult tasks, and fewer problem behaviours. However, the results of the present study as well as those of Vause et al. (1999) suggest that tasks below a client's ABLA level (and presumably therefore considered easy) may also be associated with problem behaviours. Perhaps the "easy tasks" in studies cited by Horner et al. that used the interspersal strategy were tasks that were at a client's ABLA level, rather than below a client's ABLA level. Future research might examine this possibility.

In summary, prior to learning about the ABLA test, instructors frequently provided clients with training tasks that were above and below the ABLA level of clients, which resulted in more aberrant behaviour than tasks that were matched to the ABLA level of clients. When instructors learned about the ABLA test via a self-instructional manual, and were given minimal prompting, they did a much better job of matching ABLA level of clients to the ABLA difficulty of training tasks, and aberrant behaviour of 9 of 13 clients decreased. Future studies should explore this finding in naturalistic settings. Reduction of aberrant behaviour in such settings is likely to contribute to quality of life for persons with developmental disabilities.

Acknowledgments

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An Investigation Into the Characteristics of the Maltreatment of Children With Developmental Delays and the Alleged Perpetrators of This Maltreatment

Ann Fudge Schormans and Ivan Brown

Abstract

Developmental delay is over-represented among those children who are reported to child welfare agencies for abuse and neglect. Little comprehensive information is available regarding the pattern of maltreatment (type, frequency, and duration), who the perpetrators are, and perpetrator-related factors that are related to maltreatment. This study compared the 666 children with developmental delay and the 7,006 non-delayed children from the Canadian Incidence Study of Reported Child Abuse and Neglect. Compared to the non-delayed children, those with developmental delays experience more maltreatment, particularly neglect, over longer periods of time and are more likely to have multiple perpetrators. Perpetrators for all children are most likely to be family caregivers — mostly biological parents or one biological parent and one other. The caregivers of children with developmental delays, compared to those without delays, are more likely to have lower education, rely on social security, have low family income, live in rental housing and live in unsafe conditions. In addition, these caregivers have higher rates of cognitive impairment, mental health problems, physical health problems, drug abuse, criminal activity, social isolation and being maltreated as a child. These dramatic findings point to numerous risk factors for maltreatment for children with developmental delays, a population that is already vulnerable in numerous ways.

As a group, children with developmental disabilities appear to be particularly vulnerable to maltreatment (Ammerman et al., 1989; Randall, Parilla & Sobsey, 2000; Westcott & Jones, 1999). Sobsey (2002) suggested that almost one-third of such children have substantiated histories of maltreatment while many more have probably experienced unreported or unsubstantiated maltreatment.

There is growing evidence of an association between maltreatment and developmental disability. Child maltreatment is implicated in a substantial number of developmental disabilities, and children with developmental disabilities are at an inflated risk of experiencing maltreatment (Garbarino et al., 1987; Hughes & Rycus, 1998). This is not a simple cause and effect relationship, nor is it universal and/or inevitable. According to Sobsey (1994), it can, however, create a cycle of maltreatment and disability: childhood maltreatment leading to permanent developmental disability that then precipitates life-long risk and vulnerability to further maltreatment. Three to six percent of all maltreated children will have some degree of permanent developmental disability as a result of abuse or neglect, and child maltreatment is a factor in 10-25% of all developmental disabilities (Sobsey, 1994).

A review of the literature highlights a number of characteristics of the maltreatment experiences of children with developmental disabilities. It appears that this group of children experience similar types of maltreatment as do children without disabilities. Although both disabled and non-disabled children who are reported for maltreatment frequently experience multiple forms of maltreatment, either simultaneously or at different times or ages, it is suggested that children with developmental disabilities do so at a significantly higher rate (Sullivan & Knutson, 2000; Verdugo, Bermejo & Fuertes, 1995). The maltreatment of children and adults with developmental disabilities is believed to be more severe than for people without developmental disabilities, especially in the case of sexual abuse (Ammerman et al., 1989; Beail & Warden, 1995; Sobsey, 1994; Sobsey & Mansell, 1994; Tharinger, Burrows & Millea, 1990). In addition, people with developmental disabilities appear to experience more physical injuries and emotional harm as a result of maltreatment (Ammerman et al., 1989; Sobsey & Mansell, 1994; Tharinger et al., 1990). Higher rates of chronic abuse and neglect are also documented for this group, as they are more likely to experience multiple episodes of maltreatment spanning a longer period of time. For example, Sullivan & Knutson (2000) found that 71% of their sample of children with a developmental disability reported repeated abuse, as contrasted with 60.1% of their sample without a developmental disability.

Increasingly, the literature suggests that for children with disabilities the alleged perpetrator of maltreatment is frequently a family member

(Ammerman et al., 1989; Beail & Warden, 1995; Perlman & Ericson, 1992; Sobsey, 1994; Sullivan & Knutson, 2000; Tharinger et al., 1990). Despite this, there appears to be a perception in the general population that maltreatment of children with developmental disabilities (especially sexual abuse) occurs, to a considerable extent, at the hands of strangers or non-family members (Orelove, Hollohan & Myles, 2000; Tharinger et al., 1990). This perception likely stems from two sources: first, there is some evidence that the maltreatment of adults with developmental disabilities, including sexual abuse, is often perpetrated by non-familial paid caregivers; and second, there is evidence that sexual abuse in the general population is sometimes perpetrated by strangers.

A number of studies suggest that the maltreatment of people with disabilities is perpetrated by paid caregivers who gain access and opportunity to this group of individuals directly through the disability service system (Brown, Stein & Turi, 1995; Mansell, Sobsey, Wilgosh & Zawallich, 1997; Sobsey, 1994; Sobsey & Doe, 1991). Sobsey (1994) reported that 56% of sexual abuse was perpetrated by service providers, compared to 28% by familial caregivers. Generalizing from such reports is difficult because people with developmental disabilities reside in a variety of living and caregiving situations. In the wake of de-institutionalization, more people with developmental disabilities are now living in their family homes, especially children. A significant number, however, still reside in out-of-home placements, including permanent settings (e.g., group homes, institutional settings) and temporary care (e.g., respite care), and multiple moves are not uncommon. One potential outcome of this kind of discontinuity of care and involvement with the disability service system is an increased vulnerability to maltreatment by non-family members (Balogh et al., 2001).

Complicating our understanding of this issue, however, is that often these studies focus solely on adults or do not distinguish between adults and children (Brown et al., 1995; Sobsey, 1994; Sobsey & Doe, 1991).

A strong emphasis in the literature, primarily during the 1990s, on childhood sexual abuse (Goldman, 1994; Randall et al., 2000; Sullivan et al., 1991; Sullivan & Knutson, 2000; Tharinger et al., 1990) may prove to have been misleading. This largely singular focus on sexual abuse, to the exclusion of other forms of child maltreatment, may have had two unforeseen consequences. First, it may have resulted in sexual abuse appearing to be a more common occurrence than it actually is. Second, while studies demonstrate that strangers are sometimes the perpetrators of childhood sexual abuse (Cupoli & Sewell, 1988; Kenny & McEachern, 2000; Romans

& Martin, 1997), inadequate attention has been paid to the alleged perpetrators of other forms of maltreatment, possibly creating a skew in our understanding of who the offenders of child maltreatment are.

The fact is we have very limited information at the present time as to who are the perpetrators of maltreatment for children with developmental delays. Making reference to the alleged perpetrators of maltreatment against children in the general population, Becker (1994) suggested that perpetrators are, generally, a very diverse group. It is no longer adequate to describe alleged perpetrators along such dichotomous parameters as offending against either children or adults; offending against family members or acquaintances or strangers; or offending in non-contact ways (i.e., exhibitionism) or through bodily contact.

Although the maltreatment of children, both with and without disabilities, has existed throughout the ages (Chadwick, 1999; Garbarino et al., 1989; Verdugo & Bermejo, 1997; Winzer, 1997), organized efforts to understand child maltreatment is a fairly recent phenomenon. In Canada, one attempt to facilitate the understanding of, and response to, child maltreatment has been the Canadian Incidence Study of Reported Child Abuse and Neglect (CIS), a national study on child maltreatment (Trocmé et al., 2001). This present paper analysed data from the CIS for a subset of 666 children identified as having a developmental delay and builds upon two previous analyses of this subset of children in the CIS (Brown, 2002; Fudge Schormans, in press). The immediate questions being asked are: 1) what is the pattern of maltreatment (type, frequency, duration) reported for children with developmental delays as compared to children without developmental delays; 2) who are the alleged perpetrators of this maltreatment for children with and without developmental delays; and 3) what perpetrator-related factors might help us to better understand the maltreatment of children with developmental delays as compared to children without delays.

Method

Procedures

This examination into the maltreatment of children with developmental delays made use of data collected for the Canadian Incidence Study of Reported Child Abuse and Neglect (CIS), Canada's first national study exploring the incidence of reported child maltreatment and the characteristics of children and families being investigated by Canadian child welfare systems (Trocmé et al., 2001). The purposes of the CIS were to examine (1) the rates of reported physical abuse, sexual abuse, neglect, emotional maltreatment and multiple forms of maltreatment; (2) the severity (chronicity and evidence of harm or risk) of maltreatment; (3) the characteristics of reported children, families and alleged perpetrators; and (4) the relationship between incidence of maltreatment and specified determinants of health. A fifth purpose was to monitor short-term investigation outcomes (substantiation and placement rates, child welfare court involvement and criminal prosecution of perpetrators) (Trocmé et al., 2001).

The CIS used a multistage stratified sampling design to, first, select a representative sample of child welfare sites and, second, to sample cases within those sites that corresponded to determined criteria regarding child maltreatment. At least one site was chosen from each province and territory having a child population under 275,000. Further stratification (by region and agency size) was employed for larger provinces. In addition, 4 provinces allocated funding to allow for over-sampling. From a field of 327 child welfare service areas, 51 sites were selected. Of the 9,936 family cases opened at these sites during a three month time period (from October 1 to December 31, 1998), 4,548 cases were screened out, resulting in 5,388 family cases involving 7,672 children investigated for suspected or reported child maltreatment. Not included in the study were those cases opened for reasons other than child maltreatment, new allegations on cases currently open at the time of data collection, cases of maltreatment not reported to child welfare, and children already in child welfare care. The child maltreatment investigation was the unit of analysis.

To gather standardized information about child maltreatment and the characteristics of maltreated children and maltreating families from the child welfare workers conducting investigations, the Maltreatment Assessment Form was developed for use as the primary data collection instrument in the CIS. The Maltreatment Assessment Form consists of three sections: 1) an Intake Fact sheet, to record information regarding the referral and identification of children referred for investigation of maltreatment; 2) a Household Information sheet, to document information related to characteristics of the child's caregiver(s) and household; and 3) a Child sheet, to report information concerning characteristics of the maltreated child and consequences of the maltreatment. The Maltreatment Assessment Form was filled out by the participating investigating child welfare workers at the completion of the child maltreatment investigation. An overall participation rate of 90 percent was achieved. Data from the Household Information and the Child sheets is the focus of this analysis.

Examination of the maltreatment of children with developmental delays was further facilitated by a component of the CIS measurement instrument, the Child Functioning Checklist. This checklist was developed as an index of the types of concerns frequently identified in child maltreatment investigations. Although this checklist was developed in consultation with child welfare workers and researchers it is not a validated measurement instrument with established population norms. Rather, it allows for documentation of child functioning concerns that workers become aware of during child maltreatment investigations. As a consequence, incidence rates are likely an underestimation of these concerns. This checklist was comprised of seventeen child functioning concerns (one of which was developmental delay) representing physical, emotional, cognitive, and behavioural issues. These child functioning concerns were identified by workers completing the Maltreatment Assessment Form as having been confirmed (by formal diagnosis and/or direct observation) or suspected but not verifiable at the time of the investigation. The categories for confirmed and suspected were collapsed during analysis as this distinction was not always made clear in all the research jurisdictions.

Participants

The analysis presented in this paper is based upon a sample of 666 children, identified as developmentally delayed on the Child Functioning Checklist of the Maltreatment Assessment Form, drawn from the total CIS sample population of 7,672 children being investigated for child maltreatment. The 666 children described as having developmental delays comprise 8.68% of the total sample. Significantly more of the children labelled as having developmental delays are boys (60.9%) than are girls (39.1%). This over-representation of boys with developmental delays is found across all age categories. The mean age of children labelled developmentally delayed in the sample is 7.2 years (SD=4.26). 19.52% of the group of children identified as having developmental delays are also described as having additional physical or developmental disabilities, compared to 1.76% of children without developmental delays. A large majority (91.9%) of children reported to have developmental delays live with their biological parents. The rest were reported as residing with foster parents, adoptive parents, step-parents, or others.

Results

Categories of Maltreatment Reported

The four main maltreatment categories addressed by the CIS are physical abuse, sexual abuse, neglect/failure to provide, and emotional maltreatment. The CIS Maltreatment Assessment Form collected information on up to three categories of maltreatment per investigated case. For example, some children may have been reported to child welfare for a single category of maltreatment (e.g., sexual abuse) whereas other children may have been reported for two or more categories (or types) of maltreatment (e.g., physical abuse, emotional maltreatment, and neglect). The percentage of children with and without developmental delays reported for these three categories of maltreatment are shown in Table 1. Overall, children with developmental delays were more likely to be reported for multiple categories of maltreatment (34.8%) than were children without developmental delays (23.1%). Neglect is the most frequently reported single type of maltreatment for all children, across the primary, second, and third maltreatment classifications. As a primary maltreatment type, physical abuse is the second most frequently reported, with about one-third of all children reported for this type of maltreatment. For the second and third maltreatment classifications, however, emotional maltreatment is the second most frequently reported maltreatment type for all children. Sexual abuse is reported least often for all children across all maltreatment classifications.

A series of chi-square analyses were conducted to contrast the number of children with and without developmental delays reported for each of the four types of maltreatment and each of the three maltreatment classifications. There were significant differences between the two groups of children within the primary maltreatment classification, with children with developmental delays reported for more neglect (χ^2=14.460, p<.001) but less emotional maltreatment (χ^2=13.037, p<.001) than children without developmental delays. This finding was repeated in the second maltreatment classification as children with developmental delays continued to be reported more often for neglect (χ^2=13.911,p<.001) and less often for emotional maltreatment (χ^2=4.781, p<.05). In the second maltreatment classification, children with developmental delay were also less frequently reported for physical abuse (χ^2=4.510, p<.05). The two groups of children did not differ statistically for reported types of maltreatment in the third maltreatment classification.

Table 1. Percentage of Children With and Without Developmental Delays Who are Reported for Multiple Categories of Maltreatment

	Maltreatment Classification					
	Primary (%)		*Secondary (%)*		*Third (%)*	
	No Delay	*Delay*	*No Delay*	*Delay*	*No Delay*	*Delay*
Category of Maltreatment						
Physical Abuse	30.8	29.1	12.3	8.3*	9.2	7.6
Sexual Abuse	10.4	9.9	5.5	4.7	6.0	6.8
Neglect	41.8	49.4**	45.4	6.2**	42.5	46.2
Emotional Abuse	7.0	11.6**	36.9	30.8*	42.3	39.4

*p<.05, **p<.001

Maltreatment was also more likely to be substantiated for children with developmental delays than for children without developmental delays. This difference was found to be statistically significant ($p<.01$) for all three maltreatment classifications. For children with developmental delays, the substantiation rate for the primary category of maltreatment was 51.7% compared to 46.0% for non-delayed children. The rate of substantiation for the second maltreatment category was 56.2% for children with developmental delays and 46.9% for children without delays. For the third maltreatment category, substantiation for children with developmental delays was 65.2% as contrasted with 56.9% for children without delays.

Duration of Maltreatment

The majority of children in the study are less likely to experience a single incident of maltreatment and more likely to experience multiple incidents of maltreatment over a period of time (see Table 2). Within the primary maltreatment classification, the duration of maltreatment for children with developmental delays was significantly different for children with and without developmental delays (1, $p<.001$). Fewer children with developmental delays were reported for a single incident of maltreatment (13.3%) and more were reported for maltreatment lasting longer than six months (52.6%) than were children without developmental delays (23.1% and 40.9% respectively). A similar finding was found for the second maltreatment classification ($\chi^2=22.243$, $p<.001$). No statistically significant difference was found in the duration pattern of the two groups of children for the third maltreatment classification.

Table 2. Duration of Maltreatment for Children With and Without Developmental Delays Across Three Maltreatment Classifications

	Maltreatment Classification					
	Primary (%)		*Secondary (%)*		*Third (%)*	
	No Delay	*Delay*	*No Delay*	*Delay*	*No Delay*	*Delay*
Duration of Maltreatment						
Single Incident	23.1	13.3	10.1	4.0	6.8	4.0
< 6 Months	18.4	19.8	17.2	16.5	13.5	12.9
> 6 Months	40.9	52.6	54.6	67.6	64.5	69.4
Unknown	17.6	14.3	18.1	11.9	15.2	13.7

Alleged Perpetrator of Maltreatment

The operational definition of "alleged perpetrator" in the CIS refers to the individual who is alleged, suspected, or guilty of child maltreatment. The alleged perpetrator for all children in the CIS study is most often the primary caregiver, and, more specifically, this primary caregiver is typically a biological parent (see "relationship to investigated child" in Table 5). For children without a developmental delay, 95.8% of primary caregivers are a biological parent. For children with a developmental delay, the rate of primary caregivers who are biological parents is slightly lower (91.9%), and this group is slightly more likely to have alternative caregivers (i.e., adoptive parent, foster parents).

Table 3 shows the alleged perpetrators across the three maltreatment classifications for children with and without developmental delays. Again, there were differences between the two groups of children. The frequency with which the biological mother was reported to be the alleged perpetrator of maltreatment was significantly higher for children with developmental delays than for children without delays in the primary maltreatment classification ($\chi^2=11.693$, $p<.01$), second maltreatment classification ($\chi^2=12.805$, $\chi<.001$), and third maltreatment classification ($\chi^2=7.639$, $p<.01$). For the primary maltreatment classification, the foster family was also identified as the alleged perpetrator more frequently for children with developmental delays than without delays ($\chi^2=5.761$, $p<.05$), although the reported frequency was low. Another relative was more frequently reported as the alleged perpetrator for children with developmental delays than without delays in the third maltreatment classification ($\chi^2=4.189$, $p<.05$).

Table 3. Percentage of Alleged Perpetrator of Maltreatment for Children With and Without Developmental Delays Across Three Maltreatment Classifications

	Maltreatment Classification					
	Primary (%)		*Secondary (%)*		*Third (%)*	
	No Delay	*Delay*	*No Delay*	*Delay*	*No Delay*	*Delay*
Alleged Perpetrator						
Biological Mother	60.7	67.4**	66.2	76.0*	69.8	81.6**
Biological Father	40.4	37.4	41.3	43.1	42.7	38.2
Stepmother	4.1	5.1	5.4	4.7	5.0	4.4
Stepfather	6.5	4.8	5.8	4.1	7.8	8.8
Adoptive Parent	.4	.9	.5	.0	.5	.0
Foster Family	.3	.9***	.2	.6	.0	.0
Other Relative	6.5	6.3	5.3	7.0	5.0	9.6***
Stranger	.4	.3	.3	.0	.3	.0
Unknown	1.1	1.5	.4	1.2	.7	.0
Other	5.0	5.0	3.4	2.3	.0	.0

**p<.001, **p<.01, ***p<.05*

Multiple Alleged Perpetrators

The reported rate of multiple (two or more) alleged perpetrators for children with developmental delays is slightly higher for children with developmental delays (28.7%) than for children without delays (24%), a difference that is statistically significant ($\chi^2=5.827$, $p<.05$). As shown in Table 4, at least one biological parent is alleged to be involved as a perpetrator of maltreatment in cases involving multiple perpetrators for 99% of all children included in the study.

Table 4. Percentage of Multiple Alleged Perpetrators for Primary Maltreatment Classification for Children With and Without Developmental Delay

	Developmental Status	
	No Delay	*Developmental Delay*
Multiple Alleged Perpetrators		
2 Biological Parents	73.8%	74.3%
1 Biological Parent and 1 Other	25.4%	24.6%
2 Other Caregivers	.9%	1.0%
2 Others	.0%	.0%

Primary Caregiver Characteristics

As noted, the alleged perpetrator of child maltreatment is most often the primary caregiver. To shed further light on the characteristics of perpetrators of maltreatment, a number of primary caregiver characteristics were investigated through the CIS Maltreatment Assessment Form and are presented for primary caregivers of children with and without developmental delays in Table 5. For all children in the study, the primary caregiver is most frequently a biological parent, and most commonly 31-40 years of age. For both groups of children, the primary caregiver is overwhelmingly female, white, and claims English as a first language. The majority of primary caregivers for whom education level was recorded, reported an education level of secondary school or less.

Table 5. Percentage of Caregiver Characteristics for Primary Caregivers of Children With and Without Developmental Delay

	Developmental Status	
	No Delay	*Developmental Delay*
Relationship to Investigated Child		
Biological Parent	95.8%	91.9%
Adoptive Parent	.5%	1.8%
Foster Parent	.5%	1.5%
Step-parent/Partner	1.0%	.9%
Other	2.2%	3.9%
Age		
<18 years	.4%	.6%
19-21 years	3.8%	5.4%
22-25 years	10.3%	8.4%
26-30 years	19.9%	20.5%
31-40 years	49.1%	45.7%
41-50 years	13.3%	14.3%
51-60 years	1.7%	4.0%
61+ years	.5%	1.1%
Sex		
Female	84.5%	82.8%
Male	15.5%	17.2%
Ethno-racial Heritage		
White	71.0%	70.0%
Aboriginal	15.7%	18.8%
Black	3.9%	3.9%
Other	9.3%	7.3%

(continued)

Table 5. (cont'd)

	Developmental Status	
	No Delay	*Developmental Delay*
Language		
English	68.7%	64.2%
French	22.5%	28.0%
Other	8.8%	7.8%
Education Level		
Elementary or Less	4.8%	13.0%
Secondary or Less	39.4%	42.0%
College/University or Less	11.4%	6.5%
Unknown	44.4%	38.5%

Contrasting the percentage of primary caregiver characteristics for the two groups of children reveals differences for children with and without developmental delays. The relationship of the primary caregiver to the child was slightly less likely to be the biological mother (91.9%) for children with developmental delays than for their non-delayed counterparts (95.8%) as children with delays were slightly more likely to have a primary caregiver who was other than a biological parent. The pattern of ages for the primary caregivers was also somewhat different for the two groups, with a higher percentage of primary caregivers for children with developmental delays being age 41 and older, a trend that appears to increase after age 50. No differences were found between the two groups for primary caregiver sex or ethno-racial heritage. Although English was the primary language for the majority of both groups, French was identified as the first language by a higher percentage of primary caregivers of children with developmental delays (28.0%) than caregivers of children with no delays (22.5%) (χ^2=10.191, p<01). Important differences were also found for education level. The primary caregiver of children with developmental delays is almost three times more likely to have an education level of elementary school or less, and less than one-half as likely to have a college or university level education than the primary caregiver of children without delays (χ^2=93.789, p<.001).

Primary Caregiver Household Characteristics

Households of primary caregivers were described for five characteristics in the CIS: household family structure, family income estimate, family income source, housing accommodation, and unsafe housing conditions (see Table 6). Both delayed and non-delayed children in the study were more likely to live in a household headed by a single female parent than any other single type. Almost one-third of both groups of children resided in families that included both biological parents. The third most frequently reported family structure for both groups was one biological parent and either a step-parent, common-law partner, or adoptive parent.

Comparing the family structure for children with and without developmental delays indicated differences between the two groups of children. Compared to children without delays, children with developmental delays were less likely to reside in a family led by a single female parent and to more frequently reside in family structures other than those headed by a biological parent (χ^2=35.442, p<.001).

Many families in the study reported low annual incomes. Chi-square analyses contrasting the family income for children with and without delays revealed differences between the two groups: 35.4% of families of children with developmental delays in this study had incomes of less than $15,000 per year compared to 25.7% of families of children without delays, a difference that is statistically significant (χ^2=28.646, p<.001). Overall, families of children with delays had lower annual incomes than families of children without delays. Similarly, while the largest single primary income source for all families in the study was social assistance, unemployment or other benefits, once again differences were observed between the two population groups (χ^2=67.434, p<.001). Families of children with developmental delays are less likely to have full-time or part-time employment and more frequently cite social assistance, unemployment or other benefits as the primary source of income.

Approximately two-thirds of all children in the study reside in rental accommodation, and less than one-quarter report owning their homes. The pattern of housing type by delay / non-delay status shows that children with developmental delays are more likely to live in rental housing, and less likely to live in purchased housing than their non-delayed counterparts (χ^2=29.445, p<.001). This group of children is also more likely to be rated as living in unsafe housing conditions (32.2%) than children without delays (26.9%), a finding that is also statistically significant (χ^2=13.344, p<.01).

Table 6. Percentage of for the Primary Caregivers of Children With and Without Developmental Delays

	Developmental Status	
	No Delay	*Developmental Delay*
Household Characteristics		
Household Family Structure		
Both Biological Parents	31.4%	31.8%
Biological Parent with Step/Common-law/ Adoptive Parent	17.0%	17.3%
One Biological Parent & Other	2.4%	3.8%
Lone Female	39.3%	34.0%*
Lone Male	6.2%	5.3%
Other Family Structure	3.7%	7.7%
Family Income Estimate		
<15,000/year	25.7%	35.4%*
$15-24,999/year	20.9%	23.3%
$25-40,999/year	14.7%	10.3%
$41-57,999/year	6.0%	4.4%
$58-80,000/year	2.8%	1.8%
>$80,000/year	1.2%	.8%
Unknown	28.6%	24.0%
Household Source of Income		
Full Time Employment	39.7%	29.1%*
Part-time/Seasonal Employment	9.8%	8.2%*
Social Assistance/Other Benefits/ Unemployment	40.2%	56.5%*
Unknown Sources	9.2%	5.5%
No Source of Income	1.1%	.8%
Housing Accommodations		
Public Rental	10.3%	12.1%
Private Rental	50.4%	57.3%
Purchased Home	24.4%	17.1%
Shelter/Hotel	1.4%	1.7%
Other	4.6%	5.7%
Unsafe Housing Conditions Noted*		
Yes	26.9%	32.3%**

**p<.001 **p<.01*

Primary Caregiver Concerns

Caregivers included in the study were rated for seven caregiver functioning concerns by the social workers investigating the reported maltreatment. These concerns were also analyzed to provide additional information about perpetrators of maltreatment. The percentage of primary caregivers for children with and without developmental delays who were described by each of these concerns is presented in Table 7. Overall, caregiver functioning concerns were noted for the majority of primary caregivers of both groups of children. Three quarters of primary caregivers for the group with delays were reported as having any caregiver concerns, a rate significantly higher than for primary caregivers of the non-delayed group ($\chi^2=46.698$, $p<.001$).

Contrasting the percentages of caregivers of the two groups of children for the seven functioning concerns studied, using a series of chi-square analyses, again revealed a number of important differences between the groups. Caregiver functioning concerns were described more frequently for primary caregivers of children with developmental delays than for primary caregivers of children without delays for every category except alcohol abuse.

More than four times as many primary caregivers of the children with developmental delays as those of children without delays are noted to have cognitive impairments that might impact upon the quality of care giving provided in the household ($\chi^2=189.328$, $p<.001$). A significantly higher percentage of primary caregivers for the delayed group also are reported to have mental health issues ($\chi^2=52.703$, $p<.001$), and twice as many have physical health issues ($\chi^2=39.748$, $p<.001$) when contrasted to primary caregivers of children without delays. Drug abuse was also noted more frequently for primary caregivers of children with delays than for primary caregivers of children with no delays ($\chi^2=6.345$, $p<.05$). Also significant is a higher rate of criminal activity for primary caregivers of children with delays ($\chi^2=10.187$, $p<.01$), a group that is further reported to have fewer available social supports and/or more social isolation ($\chi^2=80.016$, $p<.001$) than primary caregivers of children without delays. Forty one percent of primary caregivers for children with developmental delay were reported as having been maltreated as a child as contrasted with 27.1% of primary caregivers of children without delays ($\chi^2=57.256$, $p<.001$).

Table 7. Percentage of Caregiver Concerns for the Primary Caregivers of Children With and Without Developmental Delays

	Developmental Status	
	No Delay	*Developmental Delay*
Multiple Alleged Reported Caregiver Concerns		
Any Caregiver Concerns	62.7%	76.0%*
Cognitive Impairment	3.8%	15.8%*
Mental Health Issues	19.4%	31.2%*
Physical Health Issues	7.1%	14.0%*
Drug Abuse	13.3%	17.7%***
Alcohol Abuse	26.4%	27.1%
Criminal Activity	9.9%	13.8%**
Few Social Supports	24.9%	40.8%*
Maltreated as a Child	27.1%	41.0%*

**p<.001, **p<.01, ***p<.05*

Discussion

The intent of this paper was to begin a comparative analysis for children with and without developmental delays along three parameters: 1) the pattern of reported child maltreatment (type, frequency, duration), 2) the alleged perpetrators of this maltreatment, and 3) the perpetrator-related factors involved that distinguish the maltreatment of children with developmental delays from their non-delayed counterparts.

Neglect is the most common type of maltreatment for both children with and without developmental delays. However, neglect is even more common for children with delays. This trend has been recognized in the literature (Sullivan & Knutson, 2000; Verdugo et al., 1995) and has, in the past, been hypothesized to be a function of the increased care demands of children with developmental delays that serve to place them at higher risk for neglect (Ammerman et al, 1989). This hypothesis, however, has more recently been criticized as inadequate to explain the maltreatment of children with disabilities (Sobsey, 1994).

Conversely, children with developmental delays are less likely to be reported for emotional maltreatment than are children without developmental delays. The reason for this may be, in part, that the data collected by the CIS underestimates emotional abuse because it is harder to detect and report, especially for children who are non-verbal or have limited communication abilities for self-reporting this type of maltreatment. Also of particular concern are the alarming findings that children with developmental delays are more likely to be reported as having experienced both multiple types and multiple incidents of maltreatment, spanning longer periods of time and inflicted by multiple perpetrators, than are their non-delayed peers.

It is interesting to note that of the four main categories of maltreatment, sexual abuse is reported least often, both for children with and without developmental delays. The reasons for this are not clear. There are, however, at least two possible explanations (which would require further investigation). It may be possible that the media and literature attention paid to child sexual abuse throughout the 1990s have resulted in an overestimation of the incidence of child sexual abuse. Conversely, this same media and literature attention may have resulted in people under-reporting sexual abuse for fear of repercussions stemming from disclosure.

Caregivers, primarily biological parents, and especially biological mothers, are most frequently reported to be the perpetrators of child maltreatment for all children. This is even more likely for children with developmental delays. In addition, while it was noted that multiple perpetrators are more often reported for children with developmental delays, it appears that biological parents are almost always alleged to be involved in these cases of multiple perpetrators. This lends support to the view that child maltreatment, for children with and without developmental delay, is most likely to occur in the family home and to be perpetrated by the primary caregiver. The finding that stranger abuse appears to be a rare event challenges the general perception that children are at greater risk of maltreatment from strangers than from their own families. A caution is warranted, however, in the interpretation of these findings. It must be remembered that, in Canada, the burden of care for children (with and without developmental delays) still rests primarily with women. The finding that biological mothers are most frequently reported as the alleged perpetrators of maltreatment of children with developmental delay raises questions regarding societal expectations of parents and support for parents of a child with a disability.

Caregiver characteristics are of particular interest because caregivers are most frequently reported to be the alleged perpetrators of maltreatment. Caregivers of children with developmental delays, compared to caregivers of children without developmental delays, have markedly more problematic characteristics. Among the primary caregivers included in the CIS, the primary caregivers of children having developmental delays appear more often to be single mothers, poor, dependant upon social assistance, and living in rental accommodation that is frequently unsafe. These caregivers are more likely to have additional concerns such as cognitive impairment, mental and/or physical health issues, lower education levels, a history of child maltreatment, problems with drug abuse and criminal activity. They are also likely to report having few social supports. These findings appear to confound any simplistic understanding of the maltreatment of children with developmental disabilities as being a function of the increased care demands related to the disability. Caregivers of children with developmental delays may have many more risk factors for child maltreatment than do other parents (eg. poverty; low levels of education; social isolation; cognitive, physical and mental health issues) and, consequently, they may be much more in need of prevention and support services. These risk factors appear to be strongly related to the socio-economic conditions of the caregiver. Further, the higher reported levels of problematic characteristics for the caregivers of children with developmental delays also suggests the possibility that maltreatment of children with developmental delays might well be less likely to occur in families with no concerns or fewer concerns.

It is possible that caregivers of children with developmental delays are more frequently identified and reported because they are involved with social service agencies due to their child's disability. The differential rates of caregiver concerns for caregivers of children with developmental delays and caregivers of children without developmental delays might reflect variable rates of assessment as opposed to actual differences in rates of caregiver concerns. In addition, although there appears to be an association between poverty and child maltreatment, poverty does not cause maltreatment, and the imbalance of caregivers living in poverty who are alleged to be perpetrators of child maltreatment might indicate primarily the ability of wealthier caregivers to stay out of the child protection system (Macdonald, 2001). These possibilities need to be tested carefully in future research.

The analysis conducted here was limited by the design and the data collected in the CIS. The results obtained are likely an underestimation of the maltreatment of children with developmental delays as the methodology of the CIS excluded cases already open in child protection services at the time of data collection and did not include cases of child maltreatment not reported to child protection services. As a result, the CIS does not include those cases of extra-familial child maltreatment reported to the police, a fact that may cloud our understanding of who the perpetrators of the maltreatment of children with developmental delays are. Further, the CIS is purely descriptive and, as such, cause and effect cannot be inferred from the results obtained in this analysis. Still, the CIS represents the first comprehensive set of data in child maltreatment in Canada, and thus provides an important source of information.

Analysis of the CIS demonstrates that 8.68% of the CIS sample population were children with developmental delays yet only about 1-3% of the general population is expected to have a developmental delay (Brown, 2002). This finding alone suggests the need to understand the maltreatment of children with developmental delays more fully.

Many possibilities for future research are suggested by the present analysis. The following three appear to be timely for children with and without delays. First, it is important to track both the incidence of the types and the patterns of maltreatment over time. Second, the sources of maltreatment (who the perpetrators are) need to be tracked over time for the various types and sub-types of maltreatment. This might have particular relevance for the category of sexual abuse and resolving the debate in the literature as to whether child sexual abuse is more likely to be perpetrated by family members, paid caregivers, or someone else (Mansell et al., 1997; Miller Perrin et al., 1999; Romans & Martin, 1997; Sullivan & Knutson, 2000). In addition, further analysis of perpetrators could include a comparison of those children with developmental delays being raised in their family homes by their biological parents with those children with developmental delays being raised in alternative settings by substitute caregivers. Third, the present analysis highlights the need to explore the relationship between caregiver characteristics and the maltreatment of children with developmental delays in more detail. Other research that might prove to be of interest includes: the relationship between maltreatment and single-caregiver versus two-caregiver families; the relationship between cognitive delay in caregivers and the maltreatment of children with delays; and the relationship between the level of supports available to families with a child with a developmental delay and child maltreatment.

This analysis has been a nascent attempt to better understand the maltreatment of children with developmental delays. A number of interesting patterns in the maltreatment of this group of children have been identified. In addition, this analysis has revealed several relationships between the maltreatment of children with developmental delays and the characteristics of the alleged perpetrators of this maltreatment, relationships that warrant a more thorough investigation. Nonetheless, the analysis has contributed to our understanding of the maltreatment of this particularly vulnerable group of children.

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Hope in Families of Children With Developmental Disabilities

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Abstract

The focus of this study was to explore and understand the experiences of hope in families of children with disabilities. Based on a qualitative research design, nineteen parents participated in this study. Eight common themes have been identified within participants' descriptions during the process of data analysis. Hope has been identified as a positive transformation and dynamic process that helped parents to reframe their lives in view of their experience with children with disabilities.

The way families deal with the experience of childhood disability has been the focus of diverse studies in the past two decades (Barnett & Boyce, 1995; Donovan, 1988; Gallagher & Vietze, 1986). Although stress and despair are frequently reported as a problem for families having children with disabilities (Cameron, Dobson & Day, 1991; Dyson, 1993; Harris & McHale, 1989; Krauss, 1993), more recent researchers, along with many families themselves, have rejected these negative notions (Helff & Glidden, 1998; Sobsey, 1995; Stainton & Besser, 1998). Although many parents have reported positive changes, little research has been carried out to understand this positive adjustment to parenting a child with a disability or to determine how it can be promoted.

Hope has been found to be an important and a strong predictor of parents' acceptance of their child's disability (Juvonen & Leskinen, 1994). It has been identified as a life instinct, a complex intangible in the healing and coping process, and a prerequisite for effective coping (Jevne, 1991; McGee, 1984; Menninger, 1959). Despite increasing interest in the concept of hope, the nature and function of hope in the area of children with special needs have been neglected in the professional literature.

There have been few studies that have focused on the positive experiences a child with significant disability may generate within a family (Abbot &

Meredith, 1986; Glidden, 1993). In one study of parents of children with disabilities, parents were reported to feel a greater power to achieve their goals, an increased ability to see life from other people's points of view, more compassionate, and stronger (Scorgie, 1996). These positive experiences appeared to enable parents to better meet the needs of their children with disabilities. Sobsey (1996), however, suggested that more research needed to be done with a wider variety of families before we can generalize these findings.

The purpose of this study is to explore and understand the experience of hope for families of children with significant developmental disabilities, and to identify the circumstances that facilitate hope. It is assumed that if more could be understood about the way in which family members cope and develop their perspectives as they live with the situation of a child with disability, it would be possible to identify strategies that could be used by health care providers and related professionals to enhance hope in the members of a family challenged by a child's disability. The strategies would then be driven by the actual experiences of those living with the situation rather than by a professional determination made at a distance from the experience.

Method

Procedures

A qualitative research design, using a case study approach, was used due to the exploratory nature of this study. Such a design has been recommended for researching relatively unexplored topics such as hope (Farran, Herth & Popovich, 1995; Field & Morse, 1985). Case studies are particularistic, descriptive, and heuristic in that they rely heavily on inductive reasoning in the handling of multiple data sources. The case study method does not claim any particular methods of data collection or data analysis (Mirriam, 1988; Yin, 1989). A collective case study is an instrumental study extended over several cases to manifest the common characteristics. In the study under discussion here, a collective case study approach, extended to several cases, was selected to better understand the experience of hope in parents of children with disabilities.

Participants and Data Collection

Two types of interviews were used to increase the diversity of the study participants: face-to-face interviews and internet interviews. Parent participants for the face-to-face interviews were contacted through various service associations, rehabilitation centres, and community members. These interviews were conducted after having obtained written consent from the potential participants. To recruit parent participants for the internet interviews, details of the study were posted on the internet along with the interview protocol and instructions for potential participants. The internet participants responded according to the interview protocols on the internet. A total of 19 parents participated in the study. Eight parents participated via face-to-face interviews and 11 parents responded to the interview protocol via the internet. The internet posting helped to achieve diversity of experiences, age, education, religion, and country of origin of the participants. Overall, children of the participants ranged in age from 3-18 years, and presented with a variety of disabilities (Down syndrome, autism, Joubert syndrome, muscular dystrophy, and Asperger syndrome).

An interview guide was prepared by the investigators as a framework for the data collection. The following questions were asked of the parents to explore hope in their experience of having special needs children.

1. Regarding your experience as parent of a child with disability, what does hope mean to you?
2. What would I need to know about you to better understand your feelings about hope?
3. Can you think of any events that have either enhanced or diminished your feelings of hope?
4. Can you think of any things that family and friends did that made it harder or easier for you to be hopeful in regard to your child? If so, what were they?
5. Can you think of any things that professionals or service providers did that made it harder or easier for you to be hopeful in regard to your child?
6. Is there anything you do on regular basis that strengthens your feelings of hope?

Face-to-face interviews were audio taped with the prior consent of the study participants. Interviews were transcribed and analyzed using a constant comparative method of coding and categorization (Glaser & Strauss, 1967). At first step, an individual case analysis was done to understand each case by searching for individual patterns and themes. Secondly, a search for patterns across-cases was conducted to identify common themes in the data. There were no preconceived ideas into which the data were structured to fit. Alike responses of participants helped to determine the definition of a category. Inter-coder reliability (common findings of the data analysis conducted by more than one person) added rigor and trustworthiness to the findings. In this study, constant comparative methodology helped to identify eight invariant themes of hope.

Emergent Themes

The analysis of parents' interviews revealed that each family's experience of having a child with a disability is unique in light of their specific circumstances, the nature of the child's disability, and available resources and support for the family. The initial experience was described as frustrating, shocking, and challenging, but this experience evolved into emotional strength, meaningfulness in life, and personal growth with the passing of time. Not surprisingly, hope was threatened when an unexpected future was presented. A mother of a daughter with Down syndrome expressed her initial feelings of shock followed by strength:

> *When she was born I was not expecting a baby like her and you know...no one expects things like that. I had already two healthy babies and when she [doctor] told me about her condition...I went into shock. It was the most difficult time of my life. In the presence of others I used to feel myself strong but...while alone...I used to cry a lot...but this period did not prolong much. I felt myself stronger and stronger with the passing of days.*

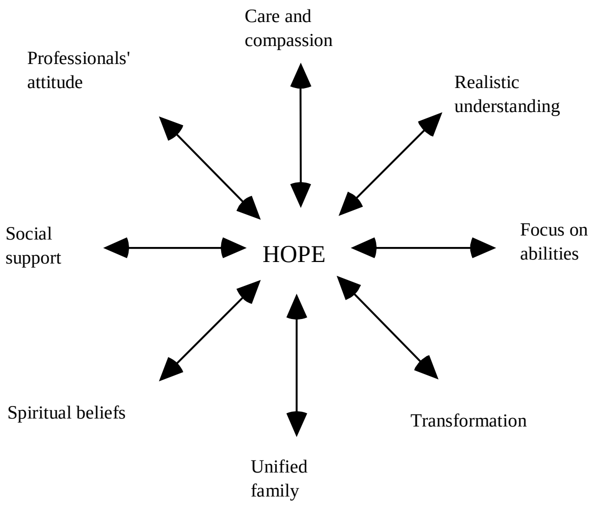
However, many elements of the experience of childhood disability were common among most, or all, of the participants. The following eight themes were identified as experiences of hope derived from the data provided by the parents' descriptions of their personal experiences of having a child with a disability (see Figure 1).

1. Care and Compassion

Parents' narratives reveal that their experience of having a child with a disability enabled them to feel compassion, love, care, and value for life. The experience reportedly enriched their lives. As a mother of a child with autism narrated:

> *I remind myself that every human life is valuable and important, that people who are nonverbal "have a lot to say," and that my son's autistic perspective is as valid as my non-autistic perspective, but it's different. I try to open myself up to just "being" with him (a state of relaxation, appreciation and acceptance).*

Figure 1: Emergent Themes



This particular theme revealed that, for the participants of this study, parenting a child with a disability helped to facilitate a hopeful attitude, empathy, love, and compassion in the families of these children.

2. Realistic Understanding

The second theme portrayed parental hope as including an acceptance of the reality regarding the child's disability condition. One father expressed his concern and understanding of his child's disability based upon realistic hope:

> *The most important thing in my life is that I ask my doctor what is his expectancy in life...whether he will be all right or he is gonna be a handicap throughout life. So my only hope is as long as he lives...he live a comfortable life...then I am satisfied. That's why I don't believe in things or do not hope something that is not possible so the hope was not dead but I accepted the fact.*

A set of parents with two children having significant disability spoke of the challenges and turning points in their lives. Their determination and hopeful perspective helped them in finding solutions.

> *All the way along over time, there were challenges that came up with both boys, but we always believed that there were solutions to those challenges. We were always looking for the answers to those challenging questions and challenging situations.*

These descriptions were regarded as evidence of the value of an approach grounded in reality for parents raising a child with disability. Parents' experiences in this study revealed that acceptance of the facts related to the disability and determination to provide a comfortable life to the child were assets stemming from having realistic hope.

3. Focus on Abilities

Most of the parents' responses shed light upon the idea that one source of hope was the abilities, rather than the disabilities, of their children. A mother attributed her daughter's innocent manners and selfless love as a source of inspiration for her:

> *There are so many other things...so many. Her good physical health, her talks, her loving nature, her smile, all these give me hope that she can live an independent life with some support.*

Another parent said:

> *...and then for two or three years she started to learn how to chew and it was...to think back on where she started from and to where she is now, is quite amazing.*

This theme reinforced the idea that a positive focus may lead towards hope and resilience in everyday life experiences for parents of children having disabilities.

4. Transformation

Parents experienced a positive personal transformation, enhanced personal resources, increased tolerance, and emotional stability as a result of their parenting a child with a disability. A father talked about his increased sensitivity and respect for life:

> *It strengthened my belief in myself…it has made me a tolerant person. I have become emotionally more stable and I can see that most of the experiences I have had a positive influence on me.*

Another parent gave the credit of her own growth to her daughter with Down syndrome:

> *In the very beginning, whenever I saw a healthy newborn baby I had a deep strange sense of loss that is not easy to describe but, now, I thank God for this blessing that enabled me to understand the reality of life.*

Parents' accounts provided credence to the view that a hopeful picture of the self was a reward of their interaction with their child. These findings provided a rare insight into the lives of those families who viewed the child as a gift within a growing and strengthening experience.

5. Unified Family

It was clear within parents' narratives that they understand their child's disability to be a source of unification and cohesion within the family despite challenging situations. One father delineated the sharing of family members:

> *My mother and sister, whenever they came, they appreciated and encouraged our commitment with the kids. We have an intact family and we basically share.*

For another parent, spousal support was a distinct coping resource to deal with the challenge of the child's condition:

> *I think that it's made my husband and myself closer. We celebrate her accomplishments with our extended family, parents, and in-laws. I guess it made us more conscious of things like quality family time and doing things together.*

The present theme supported the notion that spousal support and an extended family's positive attitude, sharing, and practical help was a source of hope and satisfaction for the parents' immediate family members.

6. Spiritual Beliefs

Spiritual beliefs and a sense of purpose in life offered a way for parents to define, or interpret, their child's disability in a positive way. Their philosophy of life and their faith led them to believe that they had been especially selected to provide comfort and care to the child.

> *I believe that you're never given anything in life that you can't handle, and, to some degree, I think there's always a purpose in life for everything. Maybe there was another meaning behind having a child with a disability, maybe it was so that later in life I would be a stronger advocate for other people as well as my daughter.*

A mother expressed her beliefs:

> *I feel that children are gifts and God doesn't make mistakes. In society's eyes she is not perfect but in our eyes, she's just as perfect as our son. We enjoy her accomplishments just as much as we enjoy our son's accomplishments.*

The parents' belief system and spirituality served as a coping resource for the challenge of rearing a child with disability and, for the families in this study, appeared to enhance and maintain hope.

7. Social Support

The availability of social resources and the sharing of common experiences was reported to be a major contributor to resilience and hope for the parents of special needs children in this study.

> *I get together with other parents who have children with similar diagnoses as mine and I find that that's very strengthening and positive to see other positive situations where their children are. It helps me keep on track.*

This theme indicated that parents of children with disabilities did not perceive themselves to be socially isolated. The social network of families sharing compassion and similar experiences was a strong support for them.

8. Professionals' Attitudes

A mixed reaction towards the attitudes of professionals was found in the descriptions of parents with special needs children reported here.

> *In terms of medical professionals, we had some situations that were just unbelievable, unbelievably bad, and some situations on the other hand that were wonderfully supportive.*

Some of the accounts indicated professionals' helping attitude in a time of need.

> *The clinicians, other health care professionals and handicapped children's services have been very helpful in providing information and other professional help to reduce the anxieties of the parents.*

This qualitative study revealed a mix of reactions among parents toward professionals that indicated professionals need increased sensitivity and empathic understanding within the realm of childhood disability.

Discussion

The findings revealed hope as a dynamic process that helped parents to reframe their lives in view of the experience of having a child with special needs. Most of the parents reported that accompanying a child with a disability on the road to life became a positive and strengthening experience for them. Findings also supported the recent research that having a child with disability contributed to personal and spiritual growth, family stability, and personal hopefulness (Behr & Murphy, 1993; O'Conner, 1995).

Though variability existed in the experiences of parenting a child with a significant disability (in view of many factors such as social support, philosophy of life, and the personal characteristics of the parents), the findings reported here reflected upon the brighter side of the picture. Parents' descriptions revealed how their own experiences with their child with a disability shaped their overall experience of hope in life. For the parents in this study, hope was strengthened by both their internal (belief system, motivation, rationality) and external (family, friends) resources. Parents recognized their inner potential, their hidden qualities that enabled them to deal with their child's disability. They reported having redefined and reframed their role as parents after the birth of their child with disability. This process provided them a sense of strength, transcendence, and meaning in life.

A mixed reaction toward family, friends, professionals, and community members was also found in this study. On one hand, family and friends' support enabled parents to better meet the needs of their child with a disability. As a result, parents developed a strong motive to share and celebrate the rewards of their children’s small gains with others. They frequently celebrated these gains with grandparents and extended family. On the other hand, service providers' and professionals' negative evaluations of the child's disability reportedly made parents feel hopeless for the child's future. Although parents negative experiences with professionals have been the focus of other studies, more research is required to determine the ways to increase positive and hopeful interactions between parents of children with disabilities and the professionals they rely upon for support.

Although positive experiences of disability are not ubiquitous in the special education literature, they do exist. Recently, Helff & Glidden (1998) reviewed family adjustment research over a 20-year period to determine the negative and/or positive conceptions of families rearing children with developmental disabilities. The authors found that there occurs a move from a less negative to a more positive portrayal of this group of families taking place in the literature between the 1970s and the 1980s/1990s. Although this change is not significant, it does reflect a shift in paradigms over time.

The findings presented here suggest that hope and positive transformation are meaningfully interconnected in the lives of parents of children with developmental disabilities, and that further research exploring the positive attributes of hope may be highly valuable for these families and for professionals in the field of special education.

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Human Rights and Persons With Intellectual Disabilities: An Action-Research Approach for Community-Based Organizational Self-Evaluation

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Abstract

Persons with intellectual disabilities have historically been denied their rights or experienced severe rights restrictions. In recent decades there has been a shift towards the respect for the rights of persons with disabilities. However, there are still rights restrictions that may be in place in today's systems. Agencies supporting persons with intellectual disabilities are beginning to establish commissions on human rights to review restrictions when they occur and to ensure that such restrictions are either justified or removed. These restrictions may be in place to protect the individual, or they may represent restrictions or violations that have no justification. There has, however, been no systematic research into the nature of rights restrictions that exist in systems that support persons with intellectual disabilities. In this research, an agency that was initiating a rights review process asked the critical baseline question: What rights restrictions exist in the agency? Using staff questionnaires and interviews with individuals with disabilities, the more commonly rated rights restrictions were identified within the agency. The data, however, indicate that staff (primary and part-time) and the individuals identified different rights restrictions and had significantly different ratings of these restrictions.

Historically, persons with intellectual disabilities have been denied the right to live in the community, marry, procreate, work, receive an education, and, in some cases, to receive life-saving medical treatment. They have been subjected to incarceration, sterilization, overmedication, and cruel or unusual punishment (Scheerenburger, 1983). However, recent history has seen an increasing concern for the way in which people with intellectual disabilities have been treated. This article describes the results of a survey of human rights awareness that was conducted with individuals and their care providers in an Association for Community Living. This action research is part of an ongoing program focused on the implementation of an organization-wide human rights training program (see the article by Owen et al., this issue).

The word "rights" is used here in the sense of human (natural) rights, a term that implies entitlement to such things as food, shelter, a non-threatening physical environment, security, health, knowledge, work, freedom of conscience, freedom of expression, freedom of association, and self-determination (Bayles, 1981). These entitlements are considered to be independent of previous conduct or social position. They cannot be lost. They are not absolute, and they do not necessarily override other considerations (Bayles, 1981). Stratford (1991) explained:

> *Each and every human life is equally sacred; each one of us is of infinite worth. To regard the life of a human with a mental or physical handicap as being less valuable than the life of a normal human being is to violate this fundamental notion of equality.(p. 11)*

In North America, rights and freedoms are guaranteed in many ways through vehicles such as the Canadian Charter of Rights and Freedoms, and the Declaration of Independence and the Americans with Disabilities Act (1973) in the United States. Rights are further protected through international agreements that Canada and the United States have signed, including the United Nations Universal Declaration of Human Rights (1948), the United Nations Declaration on the Rights of Mentally Retarded Persons (1971), and the Declaration on the Rights of Disabled Persons (1975) (see Rioux & Carbert, this issue for further details).

Rights Restrictions

Rights declared in law are inalienable and, as such, persons with intellectual disabilities should have access to them by virtue of their being. For example, the 1984 revisions to the Ontario Human Rights code declared the rights for all persons who had disabilities, and the Canadian Charter of Rights and Freedoms provides equal rights before and under the law regardless of disability (Neuman, 1984). Yet some of the rights outlined in the Declaration of Human Rights for Disabled Persons are routinely violated, ignored, or restricted for persons with intellectual disabilities. Some examples include access to (Stratford, 1991):

- medical care, physical therapy, and other education, training rehabilitation and guidance that allow people to develop to maximum potential
- productive work, economic security, and a decent standard of living
- living with their own family, or other situations of their choice
- qualified guardians
- protection from exploitation and abuse

In law, no person can be physically detained, controlled, or restrained arbitrarily. However, this is often done in programs serving persons with disabilities. Examples include: a person with disabilities wishing to associate with others of his choice but not being allowed to do so; a person wishing to take part in religious practice but having no opportunity to do so; a person wishing to leave her/his home but is refused the right to do so; or a person who is physically or chemically restrained. From the perspective of the right to be free of cruel and unusual punishment, one might argue that aversive interventions to treat individuals who self injure is a violation of one's basic rights (Weagant & Griffiths, 1988). Yet, within services for persons with intellectual disabilities, rights restrictions that are imposed on organization members are not typically monitored.

In the literature, there are no documented studies to be found that examine system-wide human rights restrictions on persons with intellectual disabilities. In the present study, a review was conducted of the human rights restrictions that existed in Community Living - Welland/Pelham (CLWP). The review was initiated by the organization's Executive Director as a baseline for the development of a system-wide change that was designed to create increased empowerment and personal goal setting for all individuals.

Method

Participants

Individuals supported in the four types of residential settings operated by CLWP were given the opportunity to participate. The settings included Group Homes, Semi-Independent Living (SIL), Family Homes, and Specialized Group Homes. Group homes were described as locations with maximum support and multi-bed settings (three or more). SIL consisted of minimum support settings where the individual lived alone or with others in the community with part-time staff support where needed. Family Home Programs involved placement of an individual within an existing family in the community. Specialized Homes were often individually designed residences of one or two individuals who experienced special needs. The supports in these Homes varied based on individual need.

At the time of this study, 120 persons were supported by CLWP in the four types of residential settings (56 lived in Group Homes, 22 in SIL, 33 in Family Homes, and 9 in Specialized Group Homes). Interviews were conducted with 74 out of a possible 120 individuals (32 lived in Group Homes, 15 in SIL, 20 in Family Homes and 7 in Specialized Homes). Forty-six were not interviewed for reasons including choosing not to participate, limitations in communication, providing over-compliant responses, or being away on vacation. In addition to the data gathered from individuals supported by CLWP, mail-in surveys were sent to 76 primary staff and 258 support staff.

The Survey Package

A system-wide rights survey package (Gosse, et al., 2002) was developed specifically to examine the human rights of persons being supported in community living settings. This package was developed in collaboration with individuals supported by CLWP and their staff. The Human Rights Survey consists of 80 items. Participants rate each item using a 5-point Likert-type scale ranging from disagree (1) to agree (5). Lower scores are indicative of a greater perception of human rights restrictions.

Three parallel survey forms were designed to ask the same 80 questions to three different groups within an agency: the individual being supported, the primary staff person supporting that individual, and all support staff in residential services. Each survey form asked the same questions with slight wording changes to make the survey form appropriate to those completing it.

Procedure

The survey questions were based on a literature search concerning rights of persons in the general population and specific rights for persons with disabilities. A committee of experienced agency staff developed the survey forms, and these were amended following focus group input from individuals served by CLWP, community participants, and staff and individuals who worked/lived in the settings.

All staff in the agency who were involved in residential support and all individuals receiving residential support were given the opportunity to take part in the survey. Written consent was obtained from all parties. All participants were advised that their participation was totally voluntary and that they could withdraw from the study without penalty.

Survey forms were sent to: 1) primary staff who had been approved by individuals to make comments about them, and 2) support staff in all residential settings. Of the 76 primary staff and 258 support staff, 53% of the primary staff and 29% of the support staff returned their surveys. The staff survey forms were returned by mail. Interviews regarding the survey forms were conducted with all individuals supported by the agency who consented and who were able to participate. Two interviewers conducted the interviews with the individuals supported by the agency. The purpose of this was to ensure improved monitoring for concerns such as constricted response sets (e.g., a yes or a no answer used repeatedly) or socially desirable answering (e.g., answering according to the way that they perceived the interviewer would prefer).

All data were coded for the individual and the setting, to protect participant confidentiality. After each individual was interviewed, his/her survey form was placed in an envelope and sealed. Staff survey forms were sent to a researcher at Brock University in self-addressed, stamped envelopes.

Results

Human Rights Survey - Factor analysis

The 80 questions on the survey forms assessed all aspects of a person's life and covered each area of CLWP's human rights statement. All items comprising the Human Rights Survey were subjected to a factor analysis with varimax rotation (Stevens, 2002). This analysis revealed four components with eigenvalues greater than 1.0, which accounted for 53.39% of the total variance. The majority of the intercorrelations of the factors had absolute values above .50 with a range of .40 through .79. The four factors that emerged from this analysis were *Access and Autonomy, Relationship and Community Support, Safety, Security and Privacy*, and *Control and Decision Making*.

The first factor, labelled *Access and Autonomy* (Eigenvalue=22.50), consisted of 24 items and accounted for 34.50% of the variance. The highest loadings were for "This individual can participate in any other religious activity that he/she chooses" (e.g., praying, eating specific foods, fasting, wearing religious artifacts) (.79) and "This individual uses the phone in a private place whenever he/she chooses" (.76). The second factor *Relationship and Community Support* (Eigenvalue=4.81) consisted of 21 items and accounted for 7.28% of the variance. The highest loadings were for "A staff member has given this individual medication (meds) without his/her permission in the last 12 months" (.73) and "Everyone always rings the doorbell or knocks and waits for someone to answer before entering the home" (.71). The third factor was labelled *Safety, Security and Privacy* (Eigenvalue=4.27) and consisted of 7 items that accounted 6.47% of the variance. The highest loadings were for "This individual enjoys where he/she lives" (.65) and "This individual is worried about his/her things being stolen" (.64). Finally, the fourth factor was labelled *Control and Decision Making* (Eigenvalue=3.66) and consisted of 9 items that accounted for 5.55% of the variance. The highest loadings were for "This individual is able to decorate his/her room however he/she chooses" (.66), and "If this individual is unhappy, he/she has someone to talk to other than a staff member" (.61).

Five additional items were retained that did not load on any of the four factors but were considered to be conceptually valuable. These items were thought to measure important rights restrictions (e.g., "This individual has received sexual education or is scheduled to do so in the next six months"). Three qualitative, open-ended items, which were not included in the factor analysis, were included in the survey. These items invited the participants to comment openly and freely on any issues pertaining to human rights restrictions (e.g., "There is a human rights issue regarding this individual that needs to be addressed"). Eleven items were removed from the final analysis because they did not load statistically on any of the four factors nor did they fit conceptually with the other items on the survey (e.g., "This individual is required to inform someone else where he/she is going when he/she leaves"). Following the removal of these eleven items, the *Human Rights Survey* consisted of a total of 69 items, and each participant's score was subsequently recalculated (omitting these eleven items).

Overall Differences in Rights Restrictions: Percentage of Rights Restrictions Reported by Individuals, Primary Staff and Support Staff

Overall percentages were examined for each of the final 69 items to determine the top seven human rights restrictions as reported by participants. Percentages were examined separately by type of rater including individuals, primary staff, and support staff and across each of the four settings, that is, SIL, Specialized Group Homes, Group Homes, and Family Homes.

Table 1 presents the top seven rights restrictions as reported by individuals receiving services, for each of the four settings. The column labeled "overall" represents the top seven restrictions rated by the total group of individuals receiving services across the four settings. The top human rights restriction reported by the overall group of raters receiving services was "Worrying about their things being stolen" (46.6%). Some interesting differences are evident in the individuals' ratings across the four different settings. First, "Worrying about their things being stolen" appeared as a top seven restriction in three of the four settings: SIL (64.2%), Specialized Group Home (42.9%), and Group Home (46.9%). However, it did not appear in the top seven for Family Homes. Second, the individuals in Family Homes rated "Cannot be alone with boyfriend or girlfriend" as the number one restriction, but this did not appear on the top seven lists for any of the other settings.

Table 1. The Top Seven Rights Restrictions Reported by Individuals Receiving Services

Top 7 Restrictions	*Overall*	*Supported Independent Living*	*Specialized Home*	*Group Home*	*Family*
1	Worry about things being stolen (46.6%)	Worry about things being stolen (64.2%)	If sad, there is no one to talk to other than staff (50%)	Cannot decide to receive medical treatment (50%)	Cannot be alone with boy / girlfriend behind closed door (70%)
2	Cannot have children if I choose (44.4%)	There are things I want to do but can't (57.1%)	Worry about things being stolen (42.9%)	Worry about things being stolen (46.9%)	Cannot have children if I choose (70%)
3	There are things I want to do but can't (44.4%)	There are things I want to change but can't (57.1%)	Cannot decide to receive medical treatment (42.9%)	Cannot have a pet if I choose (46.9%)	Need to discuss a human rights issue (53%)

(continued)

Table 1. (cont'd)

Top 7 Restrictions	*Overall*	*Supported Independent Living*	*Specialized Home*	*Group Home*	*Family*
4	Cannot decide to receive medical treatment (42.3%)	Cannot choose primary worker (50%)	Something was removed as punishment (past 12 months) (42.9%)	If sad, there is no one to talk to other than staff (46.9%)	There are things I want to do but can't (45%)
5	If sad, there is no one to talk to other than staff (40.8%)	Worry about someone hurting me (42.9%)	Cannot choose primary support worker (42.9%)	Cannot choose where I live (43.7%)	Cannot live with girl/boyfriend if I choose (45%)
6	There are things I want to change but can't (40.3%)	Do not like where I live (35.7%)	Cannot get married if I choose (33.3%)	Cannot have children if I choose (40.6%)	Want to do something different during day (40%)
7	Cannot be with girl/boyfriend with door closed (38.9%)	Staff always tell me what to do (35.7%)	Cannot have children if I choose (33.3%)	Staff always tell me what to do (40.6%)	Cannot decide to receive medical treatment (40%)

Table 2 presents the top seven restrictions as reported by the primary staff across each of the four settings. Again, the column labeled "overall" represents the top seven restrictions rated by the total group of primary staff. The top two restrictions rated by the primary staff were: "Cannot choose primary support worker" (44.1%) and "There are things they wish to change" (40.3%). Some interesting differences were revealed when the top rights restrictions reported by the primary staff across the four settings were examined. For example, in Group Homes "People do not ring bell before entering the home" (45.5%) was rated as the second top rights restriction. This item did not appear in the top seven list for the other three settings. Moreover, some notable findings were revealed in the overall magnitude of the top rights restrictions as reported by the primary staff across settings.

Interestingly, all of the primary staff in SIL (100%) rated: "There are things the person wants to change but can't" as their top rights restriction. A total of 55.5% of primary staff in Group Homes reported: "There are things the person wants to change but can't" as their top rights restriction, and a total of 50% of primary staff in Family Homes reported "Cannot take a sexuality education course if I choose" as their top rights restriction. Finally, only 28.6% of the primary staff in SIL reported that "Cannot choose primary worker" as the top rights restriction.

Table 2. The Top Seven Rights Restrictions Reported by Primary Staff

Top 7 Restric tions	*Overall*	*Supported Independent Living*	*Specialized Home*	*Group Home*	*Family*
1	Cannot choose primary worker (44.1%)	Cannot choose primary worker (28.6%)	There are things the person wants to change but can't (100%)	There are things the person wants to change but can't (55.5%)	Cannot take a sexuality education course if chooses (50%)
2	There are things the person wants to change but can't (40.3%)	Staff are not helping find job person wants (28.6%)	Cannot have a pet if chooses (66.7%)	People do not ring bell before entering home (45.5%)	There are things the person wants to change (46.2%)
3	Cannot take a sexuality education course if chooses (36.4%)	Staff do not ask before helping person dress (16.7%)	Cannot take a sexuality education course if chooses (66.7%)	Worry about being hurt (45.5%)	Cannot choose primary worker (46.2%)
4	There are things the person wants to do but can't (38.4%)	Cannot choose friends (14.3%)	There are things the person wants to change (50%)	There are things the person wants to do but can't (40%)	Cannot decide to receive medical attention (38.5%)

(continued)

Table 2. (Cont'd)

Top 7 Restric-tions	*Overall*	*Supported Independent Living*	*Specialized Home*	*Group Home*	*Family*
5	Cannot decide to receive medical attention (20.6%)	Worry about being hurt (14.3%)	Do not like where living (50%)	Cannot choose where to keep money (36.4%)	There are things the person wants to do but can't (30.8%)
6	Cannot choose where to live (18.2%)	Worry about things being stolen (14.3%)	Cannot choose where to live (50%)	Staff always tell people what to do (33.3%)	Cannot talk on phone in a private place when chooses to (30.8%)
7	Cannot choose when to go out (18.2%)	Do not like what they do during day (14.3%)	Cannot take a sexuality education course if chooses (66.7%)	Worry about being hurt (45.5%)	Cannot choose primary worker (46.2%)

Table 3 presents the top seven restrictions as reported by the support staff across each of the four settings. As with Tables 1 and 2, the column labeled "overall" represents the top seven restrictions rated by the support staff. Overall, the support staff reported their top rights restriction to be "There are things they want to change but can't" (50.8%). This was also the top restriction for the raters in both the SIL (71.4%) and Family Home settings (83.3%). Overall, there were some differences in the types of rights restrictions reported by the support staff across settings. For example, the seventh rights restriction reported by support staff in Family Homes was "Cannot choose religious setting" (55.5 %). Interestingly, this restriction was not reported as a top seven restriction by support staff in any of the other three settings.

Table 3. The Top Seven Rights Restrictions Reported by Support Staff

Top 7 Restrictions	*Overall*	*Supported Independent Living*	*Specialized Home*	*Group Home*	*Family*
1	There are things individuals want to change but can't (50.8%)	There are things individuals want to change but can't (71.4%)	People do not ring bell before entering home (69.2%)	Sent to room (past 12 months) (73.8%)	There are things individuals want to change but can't (83.3%)
2	Cannot choose where to keep money (48.7%)	There are things individuals want to do but can't (66.6%)	Not everyone knocks before entering bedroom (53.8%)	Cannot choose where to keep money (62.8%)	Chemically restrained (past 12 months) (77.7%)
3	Something was removed as punishment (past 12 months) (46.5%)	Cannot take part in sexuality education if choose (37.5%)	Chemically restrained (past 12 months) (53.8%)	People do not ring bell before entering home (64.5%)	Cannot choose when to go out (66.7%)
4	Cannot choose primary support worker (46.1%)	Need to discuss a human rights issue (25%)	Cannot decide to receive medical treatment (50%)	Cannot choose primary worker (60%)	Something was removed as punishment (past 12 months) (66.6%)
5	Given medications without permission (44.8%)	Staff is not helping find individual a job (22.2%)	Cannot choose where to keep money (46.2%)	Something was removed as punishment (past 12 months) (59.6%)	Sent to room (past 12 months) 66.6%)
6	When not at home other people go in room (43.4%)	Worry about being hurt (22.2%)	Given medications without permission (46.2%)	When not home other people go in room (57.7%)	There are things individuals want to do but can't (67.7%)

(continued)

Table 3. (Cont'd)

Top 7 Restrictions	*Overall*	*Supported Independent Living*	*Specialized Home*	*Group Home*	*Family*
7	There are things individuals want to change but can't (42.4%)	Cannot choose primary worker (22.2%)	Staff looked through person's things (38/5%)	There are things individuals want to change but can't (53.8%)	Cannot choose religious setting (55.5%)

Mean Differences in Rights Restrictions

Comparison of the means for each group of raters, across each of the four settings, revealed some interesting differences in terms of participants' reported top rights restrictions. In exploring the overall data set, a two-way ANOVA (Rater x Setting) revealed no significant interaction between type of rater and type of setting $F(6,177)=1.768$, $p=.108$; however, a significant main effect for rater status was revealed $F(2,177)=7.964$, $p=.000$. Follow-up univariate tests revealed that primary staff ($M=3.86$, $SD=.61$) and individuals ($M=3.74$, $SD=.33$) reported significantly fewer restrictions than support staff ($M=3.38$, $SD=.62$). There were no significant differences between the number of restrictions reported by primary staff and the individuals. A significant main effect was also found for setting F(3,177)=7.964,$p=.000$. Significantly more restrictions were reported in Group Homes ($M=3.45$, $SD=.56$) than in Specialized Group Homes ($M=3.81$, $SD=.40$) and SIL ($M=4.05$, $SD=.27$). Significantly more restrictions were also reported in Family Homes ($M=3.57$, $SD=.60$) than in SIL.

Triangulated Differences in Rights Restrictions: Percentage of Rights Restrictions Reported by Individuals, Primary Staff and Support Staff

Table 4 presents the top seven restrictions as reported by the individuals, primary, and support staff collapsed across the four settings. To obtain these percentages, only the responses provided by individuals, primary, and support staff that could be triangulated were examined. For example, data provided by an individual were included if data from their primary and support staff were also collected. Therefore, the comparisons made among the three raters would be expected to show more consistency than comparisons with all the staff.

Table 4. The Top Seven Perceived Rights Restrictions Reported by a Matched (Triangulated) Group (Individuals, Primary Staff, and Support Staff)

Priority	*Individual N=36*	*Primary Staff N=36*	*Support Staff N=43*
1	Cannot have children if choose (54.3%)	There are things the person wishes to change but can't (45.3%)	There are things the person wishes to change but can't (52.8%)
2	Want to do something different in the day (45.7%)	Cannot choose primary worker (44.4%)	Sent to room (past 12 months) (47.7%)
3	There are things I want to do but can't (42.3%)	The individual wants to do something different in the day (41.6%)	Something was removed as punishment (past 12 months) (45.3%)
4	Can't be alone with boy/girlfriend with door closed (42.9%)	There are things the person wants to do but can't (32.2%)	Cannot choose primary worker (44.2%)
5	If sad, I can't talk to people who are not staff (40%)	Cannot take sexuality education course if they choose (34.3%)	Cannot take a sexuality education course if they choose (42.8%)
6	Cannot decide to receive medical attention (38.9%)	Cannot choose where to live (22.3%)	Cannot choose when to go out (41.8%)
7	Worry about things being stolen (38.9%)	Cannot choose when to go out (22.3%)	Want to do something different in the day (41.5%)

Again, the data from individuals, primary staff, and support staff revealed some interesting differences in terms of the types of rights restrictions reported. For example, no individuals reported that they were "Sent to their room as a punishment," but 47.7% of the support staff rated this as a restriction. Another important difference was the tendency for individuals to consistently report fewer rights restrictions overall, as compared with the primary and support staff.

The only question on which all three survey groups in the triangulated data agreed to be a priority for the individual was that the individual wants to do something different during the day. 45.7% of the individuals rated this as a priority, as did 41.6% of the primary staff and 41.5% of the support staff. These were rated as priority two, three, and seven respectively.

Individuals rated choice of medical attention (38.9%), worry over things being stolen (38.9%), and having no one to talk to but staff when they are sad (40%) as their priority items. These were not rated as highest priorities for the staff. Two of the top priority items for individuals were not identified as widespread issues by either staff group. Worry over things beings stolen, although rated by 38.9% of the individuals, was identified by only 8.4% and 4.7% of primary and support staff respectively. Similarly, the fact that individuals had no one but staff to talk to when they were sad was noted by 40% of the individuals but only 5.8% of the primary staff and 12.2% of the support staff.

Staff members, on the other hand, prioritized two areas that were not highlighted by the individuals. First, the choice of primary workers was identified as an important rights restriction by 44.4% of primary staff and 44.2% of the support workers. This, however, was not a major priority for the individuals, being selected by only 25%. Of greater contrast was the rating of access to sexuality education. This was noted as priority #5 by both staff groups (34.3% and 42.8%) but noted by only 5.7% of the individuals. Of particular note was the identification by support staff of punitive measures taking place in their residential setting that were not identified by either the individuals or primary staff. This difference in perception may be an artifact of the fact that support staff members were reporting on general procedures and not individual-specific rights restrictions.

Mean Differences in Rights Restrictions

For the overall "triangulated" data set, a two-way ANOVA (Rater x Setting) revealed a significant main effect for setting in perceived rights restrictions $F(3,105)=7.051, p=.000$. Univariate follow-up tests revealed a significant difference between Group Homes ($M=3.58, SD=.62$) and SIL ($M=4.08$, $SD=.29$), and between Family Homes ($M=3.55, SD=64$) and SIL. The greatest number of rights restrictions were reported by individuals in Family Homes, followed by Group Homes, then by Specialized Group Homes and

SIL. A significant main effect was also found for rater status *F*(2, 105)=3.495, *p*=.034. Univariate follow-up tests revealed a significant difference between primary staff (*M*=3.87, *SD*=.62) and support staff (*M*=3.43, *SD*=.70). In this regard, the support staff reported the greatest number of rights restrictions, followed by the individuals and then the primary staff. The interaction between type of rater and type of setting was not significant *F*(6,105)=2.155, *p*=.053.

Key Findings

- Human rights restrictions in community living programs fall into four distinct categories: (i) access and autonomy, (ii) relationships and community supports, (iii) safety, security and privacy, and (iv) control and decision-making.
- The evaluation of the type and number of restrictions of rights differ significantly across different types of residential settings. In general, individuals in the SIL settings reported fewer restrictions, followed by Specialized Group Homes. The individuals in both the Family Homes and Group Homes reported the highest number of rights restrictions but were similar to one another.
- The type and number of rights restrictions also differed significantly between different groups within an organization (i.e., individuals supported by the agency, primary staff, and support staff). Individuals served by CLWP expressed concerns in all four rights domains. Primary staff placed greater emphasis generally on issues of *Control and Decision Making* and *Access and Autonomy*. Support staff also perceived the greatest rights restrictions to be focused around *Control and Decision Making* and *Access and Autonomy*, but saw issues of *Safety, Security and Privacy* as well. Interestingly, none of the staff rated issues of *Relationship and Community Support* as the top areas of rights concern, whereas these were paramount to the individuals themselves.

Discussion

This survey provided an opportunity to examine the level of human rights awareness in individuals served by CLWP and their care providers prior to the establishment of a system-wide human rights training program. It represents a moment "frozen in time" from which the organization has now moved.

The above results may be accounted for by the fact that these data were not matched but represented global data. In 36 situations, however, the data for primary and support staff could be matched to the individual and/or location, although individuals reported more restrictions in the area of *Relationship and Community Support* as well as *Safety, Security and Privacy* than did the staff.

Surveys such as the one undertaken in this study provide a forum for open, dynamic, and ongoing dialogue about human rights issues. They also challenge organization members to examine the very nature of service delivery, including current practice, policy and procedures, and staff/individual training.

As a result of the survey, CLWP has established several mechanisms to reinforce and maintain a systemic emphasis on rights protection. First, it has established a Human Rights Commission to review existing rights restrictions. Second, it has initiated a system-wide Human Rights Training Program for Association staff, managers, members of the Association's Board of Directors, and the individuals who participate in the Association's services (see the article by Owen et al., this issue). Third, feedback from the Associations Human Rights Commission will be used to review Association policy and procedures, and to direct strategic planning decisions.

It is important to recognize that the number of infringements identified through a survey of this nature does not determine that an agency is providing poor service or that the people supported have a poor quality of life. The fact that agency staff, managers, and the individuals they serve have chosen to open them to scrutiny suggests an organizational culture of commitment to continuous improvement of services. Yet, the fact remains that rights restrictions do occur in agencies. Therefore, it is critical that each rights restriction be reviewed (e.g., ensuring people are offered an opportunity to vote).

Moreover, differential identification of rights restrictions across settings may not always be indicative of rights violations as much as the design of the setting. SIL and Specialized Group Homes have been designed more closely along an individualized planning mode, where the program has been designed to fit the individual. Group Homes and Family Homes are generally designed around congregate living in which the individual is placed. Still, in these settings, it is especially important to be aware that rights may be overlooked or ignored.

Individual outcomes planning must include an examination of issues of rights restrictions. If these factors are important for the quality of life the individual chooses, then individualized plans of support need to be developed to ensure that the aspects of rights that the person desires and values are respected and monitored for access. As service systems move toward more person-centered planning, evaluation of human rights and the protection of those rights become embedded in the culture of individualized agency support. At the conclusion of this survey, CLWP adopted a strategic plan to move the agency fully toward person-centred planning.

The goal of a system-wide survey such as this is to stimulate ongoing reflection, discussion, review and revision of Association policies and procedures, and to identify areas for training and staff support. The implications of the findings from this survey can be far-reaching, impacting all aspects of an organization's functioning. This survey is a tool to assist agencies to examine areas where improvement can be made to enhance the rights and the opportunities for individuals to assert their rights. If it is misused against staff or individuals within the agency, it can violate trust and damage important lines of communication. However, if it is used in a partnership with the Board, management, staff members, and individuals in the agency, it becomes a vehicle for powerful positive social change.

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Reflecting on 14 Years of the Journal on Developmental Disabilities

Ivan Brown

As I sit down at my computer to write my thoughts about the 14 years we have published the Journal on Developmental Disabilities, the spring sunshine is streaming through my window. Spring sunshine is always so welcome, mostly because it sparks within us the anticipation of the new growth and the abundant blossoms that are surely ahead. It makes us kick up our heels a little, stray from our usual caution, and fill with optimism.

It makes me smile now, as I sit in the spring sunshine, to think of the optimism felt by those of us who produced and published the first issue of our journal in the spring of 1992. Any cautious person would have said we were jumping headlong into something we knew little about, and something that had only a chance of success. And now, I realize they would have been correct in thinking that way.

It was the members of OADD's Communications Committee of 1990 and 1991, chaired by Rebecca Ward, who took the bold step of thinking the still-new OADD could publish an academic journal. It was not the first time the idea had been mentioned – Maurice Feldman and Joel Hundert were two of those who mused, from time to time, that they might start up an Ontario-based journal that focused on developmental disabilities. But for some reason, it was that Communications Committee that moved forward, with the backing of the OADD Board of Directors. I was a member of that committee, but I do not recall precisely how I came to be the first editor of the journal. I suspect, though, it may have had more than a little to do with Rebecca's persuasion. I found it difficult to resist her requests, because she always led by the example of her own efficiency and hard work.

The first thing we did was establish our editorial team. Adrienne Perry and Ken Laprade agreed to act as Associate Editors, and others from OADD's Communications Committee acted as editorial assistants. This team set up an advisory committee, and almost immediately we simply began to plan the first issue. We settled on a name and got an ISBN to make our publication official. Gary Woodill, then a professor at Ryerson Polytechnic University and a member of our advisory committee, suggested we start off with a "bang" and invite authors to submit articles on the sexuality of people with developmental disabilities. Always one to put his "money where his mouth is" Gary also offered to write the opening article himself, an historical perspective on sexuality and disability. A few days later, he handed me his completed article, and I remember standing in my office feeling somewhat humbled, yet encouraged, because I had the first hint of a new journal in my hands.

As bold as those first warm spring rays of sunshine, I sent letters off to everyone I could think of, or had heard of, who had expertise in sexuality and developmental disabilities. Just as boldly, I sent letters of invitation to about 30 noted experts worldwide to act as members of the Review Board. I am not sure what I expected by way of response, but I remember feeling astonished that almost everyone I invited responded positively. Within a couple of months, we had moved from a vague bunch of ideas around the Communications Committee table to an editorial team, an advisory committee, a Review Board, and an enthusiastic Communications Committee and OADD Board of Directors. The first articles soon came in for review.

I was not a member of the Board of Directors at that time, but I did attend a Board meeting in the spring of 1992 as a guest speaker. To my delight and surprise, Rebecca Ward stood and held up, hot off the press, a printed copy of Issue 1, Number 1 of the Journal on Developmental Disabilities, to a hearty round of applause from the Board members.

Over its 14 years of publication, the Journal on Developmental Disabilities has covered a large number of topics, and has showcased the work of a wide array of professionals in the field of developmental disabilities. Those of us who have helped produce the journal have worked with academic and field experts from many countries. One aspect of the journal of which we are particularly proud is our commitment to helping graduate students publish some of their research results. The journal is widely available across Ontario, and its articles are abstracted in the PyscInfo database. In 2000, we began to publish online on OADD's website as well as in hard copy, and, reflecting the emerging trend for journals to be readily available in an electronic form, we began in 2005 to post articles online prior to publication, as soon as they have been accepted and formatted.

Publishing a journal has taken a great deal of hard work by a great many people. It is not possible for me to fully recognize all those people - even if my memory were reliable - but, on behalf of those who have taken some credit for the journal's production, I extend a heartfelt thank you for the many, many hours of work. This is especially appreciated because almost all this work was done on a volunteer basis, with little thought of any payback.

Three people do merit special recognition, however. Adrienne Perry was the first and longest-serving Associate Editor, and her many long hours of editorial work were invaluable in those first few years of establishing the journal. Maurice Feldman has been a long-time supporter of the journal, and served as Editor-in-Chief for a three year period in the mid-1990s. Finally, Maire Percy, who has chaired the Communications Committee of OADD's Board of Directors for the past three years as well as acting as co-Editor of the journal, has been a tireless supporter.

In 2004, I set up a Chief Editorial Board to replace the position of Editor-in-Chief. My thinking was to involve more people in the editorial work, to tap into a broader range of expertise, and to mentor less experienced academics who might not feel ready to take editorial responsibility on their own. This Board has worked very well, and serves as a model that we will probably use for some time. We need to recognize that the Chief Editorial Board has been successful primarily due to the talents and hard work of my co-members, Maire Percy, Ann Fudge Schormans, and Miles Thompson, supported by Ted Myerscough and generously backed by OADD's Board of Directors.

And so it is spring once again - this time 2006 - and once again I feel myself being filled with optimism and a tendency to stray from caution when I think of the future of the Journal on Developmental Disabilities. Simply put, I think great things are ahead for the journal. It has already become an important voice for developmental disability research in Ontario, and, in fact, in Canada, but has addressed important issues and topics fully relevant to the broader international field. The Chief Editorial Board has many new and creative ideas that will all contribute to the journal's future success. There is every reason for optimism.

As I look back over the past 14 years of publication, many of which I was involved in, it is with a sense of considerable accomplishment. It has been a great deal of work, but, from my perspective, the Journal on Developmental Disabilities has been well worth the effort. In saying this, I am confident that I am representing the views of all those who have worked to produce and publish the journal since 1992.

Well done!