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Publisher: Informa Healthcare

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Registered office: Mortimer House, 37-41 Mortimer Street, London W1T 3JH, UK



Journal of Intellectual & Developmental Disability

Publication details, including instructions for authors and subscription information:

<http://www.informaworld.com/smpp/title~content=t713432019>

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To cite this Article: Chan, Jeffrey B., Sigafoos, Jeff, Watego, Noela and Potter, Geoff, 'Adults with intellectual disability in long-term respite care: a qualitative study', Journal of Intellectual & Developmental Disability, 26:4, 339 - 344

To link to this article: DOI: 10.1080/13668250120087344

URL: <http://dx.doi.org/10.1080/13668250120087344>

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Adults with intellectual disability in long-term respite care: a qualitative study

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Although respite care is intended to provide short-term and temporary relief for caregivers, it has unintentionally become a long-term placement for some individuals with developmental disability. In an effort to understand why some individuals remain in respite care on a long-term basis, we audited the files of 10 adults with developmental disability who had been living in three respite care units for 12–24 months. Several individual (e.g., challenging behaviours, severe disability, lack of communication skills) and family characteristics (e.g., single parent/carer status, poor health, and non-English speaking background) appeared consistent across the sample. The results suggest that there may be benefit in systematic planning for respite care, especially with older single-parent families who have adult children with high support needs, challenging behaviour, and severe communication impairment.

Caring for a child with a developmental disability can be stressful for many parents (Hoare, Harris, Jackson & Kerley, 1998). Respite care is one type of support that can alleviate, to some extent, the parental stress associated with caring for a child with developmental disability (Salisbury & Griggs, 1983; Wikler, Hanusa & Stoycheff, 1986). This may be why respite care is fast emerging as a significant

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service delivery issue and as an increasingly pertinent area of research (Rimmerman, Kramer, Levy & Levy, 1989).

In addition to a growing interest, there would appear to be a growing demand for respite care services to assist families that include children with developmental disability (Castellani, 1986). This certainly appears to be the case in New South Wales, where a recent systematic and comprehensive survey identified a significant lack of services and an inequitable distribution of respite services across the state (Community Services Commission, 1998). Not only did this report find a high demand for respite care services, but it also noted that existing services were, by and large, unable to meet the needs of the many families eligible for such services.

It would seem useful to identify individuals who make frequent and long-term use of respite care. This information may enable service providers to predict the extent of use by specific individuals from the pool of eligible families. The ability to identify and predict those who will make frequent use of respite care would provide an evidence base for the provision of more suitable and effective respite services (Castellani, 1986; Rimmerman et al., 1989).

In a recent comprehensive review, Chan and Sigafoos (2000) identified several factors that distinguished users of respite care from non-users. Individual characteristics of the child that were associated with increased use of respite care included (a) severity of disability, (b) level of required care, (c) presence of challenging behaviours, and (d) communication difficulties. Certain family characteristics (e.g., level of parental stress, sources of informal support, and size of family) were also associated with more frequent use of respite care.

However, this literature as a whole had numerous limitations. For example, most of the studies reviewed by Chan and Sigafoos (2000) involved questionnaires or surveys and therefore provided indirect evidence of an association between certain child and family characteristics and the use of respite care. While questionnaire data can be robust, it would be important to further investigate factors associated with the use of respite care using additional methods, such as an audit of individual cases. In addition, while there are many types of respite care, not all studies specified the type of respite care that parents either did or did not access. Another issue uncovered in the literature review was that respite care, while generally designed for temporary relief from the burden of care-giving, may in fact become a long-term residential placement for some individuals. It is unclear if the factors that appear to influence frequent but short-term use of respite care also predict long-term placement in respite care.

The present study represents an effort to provide an additional type of evidence that may provide a check on the veracity of conclusions arising from the recent literature review by Chan and Sigafoos (2000). In this study, we audited the files of 10 individuals with developmental disability who had been living in respite care units on a long-term basis in one region of Sydney, Australia. The aim of the audit was to develop a profile of individual and family characteristics that could then be compared with the profiles of respite care users identified through the existing survey and questionnaire database reviewed by Chan and Sigafoos (2000).

The development of such a profile would be useful for beginning an evidence

base on the provision of respite care services in this region and perhaps in other regions of the city, state, and country. In addition, the focus on long-term users of respite care may help to identify factors that lead some families to make use of respite care for the long term, rather than for the intended short-term temporary relief from the burden of care-giving.

Method

Participants

The sample group consisted of 10 adults with intellectual disability living in three adult respite units. These 10 adults were selected for the study because they were all of the adults occupying respite beds in a defined region of metropolitan Sydney for a period of time greater than 12 months. The sample consisted of eight males and two females. Table 1 provides demographic information on the 10 participants and information on their family circumstances.

Table 1

Demographic Characteristics and Family Circumstances of the 10 Participants

| Name | Age | Sex | Disability Type | Disability Level | Communication | Problem Behaviour | Family Circumstances |
|------|-----|-----|--|------------------|--------------------------------------|--|---|
| TA | 19 | M | Autism | Severe | Non-speaking | Aggression, absconding, pica | NESB, in care of the Public Guardian, single parent |
| CB | 20 | F | Multiple disabilities – dual sensory impairments and physical disability, non-ambulatory | Severe | Non-speaking | None | NESB, low socio-economic status, single parent |
| CR | 24 | M | Intellectual disability and history of epilepsy | Moderate | Limited verbal skills of 10–15 words | Aggression, absconding and property damage | NESB, single parent |
| GG | 24 | M | Intellectual disability | Moderate | Verbal | Aggression | Single parent |
| TD | 32 | M | Intellectual disability | Severe | Limited verbal skills, a few words | Aggression and property damage | NESB, both parents are aged with poor health |
| EM | 38 | M | Intellectual disability | Mild | Good verbal skills | Aggression, self-injury, verbal abuse | NESB, single parent |
| FG | 20 | M | Cerebral palsy | Moderate | Good verbal skills | Aggression, absconding and property damage | Single parent, in care of the Public Guardian |
| HW | 20 | M | Autism and visual impairment | Severe | Non-speaking | Self-injury | Used to live with both parents |
| IN | 19 | F | Cerebral palsy and hearing loss | Mild | Sign language | None | Child protection issues, lived in multiple accommodation placements |
| JS | 19 | M | Intellectual disability and possible dual diagnosis | Moderate | Limited verbal skills of 3–5 words | Aggression and property damage | Single parent with poor health |

NESB = Non-English Speaking Background.

Setting

The respite service is a government agency that operates three respite care units for adults in the south-western region of metropolitan Sydney. These three units have five beds each with a total of 15 adult respite care beds. In one of these units, all five of the available beds had been occupied on a long-term basis. The second unit had three beds being used as a long-term placement and the remaining unit had two of its five beds in long-term use. This left only five beds in the entire region available for short-term and emergency respite care. The situation had created a crisis in respite services in the region. Specifically, as a result of this sample group of 10 people making long-term use of these respite beds, other individuals with developmental disability were unable to access the respite services. This crisis prompted the present review. The managers of these respite units were specifically interested in undertaking an audit to identify the characteristics of these long-term respite users so as to inform future planning of respite services.

Procedure

An audit of the 10 participants' case files was conducted to gather information on client history and family background. Specifically, we collected details on the individuals' ages, levels of needed support, and problem behaviours. In most cases this type of information was obtained from medical records as well as psychological, adaptive behaviour, and other allied health assessments (e.g., speech pathology) that were conducted previously and recorded in the individual's file. Family background details, including parental marital status, family support, and culture and socio-economic status, were also extracted from the files. The purpose of the case file audit was to identify individual and family characteristics that might be associated with long-term use of respite care. In addition to the file audit, interviews were conducted with the participants' case managers to verify information obtained from the file audit and to add any new information.

The case file audit also examined the services that had been provided to the participants. It was felt that these data might help to identify circumstances that lead to long-term use of respite care. Data collected related to intake procedures, the reason for referral, and details of the individual's habilitation plan. Once this information was obtained, the case management team was given the opportunity to check the accuracy of the information. From these multiple sources of information, a summary profile of each of the 10 participants (Table 1) was constructed.

Results

As indicated in Table 1, four participants were classified as having severe disability, four had moderate disability, and two had mild disability. In addition, two participants were described as having severe autism and one other individual was described as having a possible dual diagnosis. Five participants had additional impairments or health issues, such as a vision or hearing impairment, epilepsy, and physical disability due to cerebral palsy. In terms of communication skills, seven

participants had limited speech (i.e., a few spoken words) and three individuals were described as completely non-speaking.

Eight of the 10 individuals had a prolonged history of frequent and severe challenging behaviours including aggression, property damage, absconding, swearing, self-injury, and pica. These challenging behaviours had a clear negative impact on family functioning and had contributed to family breakdown. Indeed, the majority of the families had informed their case managers that they were unable to cope with the individual's challenging behaviours and that this was why they had placed the person into respite care and were unable to continue providing care at home.

In seven of the 10 cases, the individual with a developmental disability was under the care of a single parent, due to the death of a spouse, divorce, or separation. Four of the families did not have any informal sources of support (e.g., relatives) that they could turn to for assistance. Many of the family carers were elderly (40% were aged over 60 years of age) and had health problems. Five of the families were from a non-English speaking background. In two of the cases, the families were described as either coming from a low socio-economic background or had financial difficulties.

Given the above descriptive analysis, it might be reasonable to speculate that the following characteristics appeared to be a consistent profile in this sample. Individual characteristics included challenging behaviours and the lack of communication skills. It may be argued that higher levels of care are required because of challenging behaviours and the lack of communication skills. On the family side, the following indicators appeared consistent across the sample: (a) single parent/carer status, (b) elderly and poor health of the parents or one of the parents, and (c) the families were from a non-English speaking background.

The audit of case management file notes revealed that 60% of the original intake referrals had identified respite care and potential permanent residential placements as necessary considerations. Sixty per cent of the sample also had a history of respite care, but there did not appear to be any reviews or specific formal placement plans.

Discussion

The results of the sample study of 10 persons with developmental disability suggest certain common characteristics to the group. These characteristics were similar to those identified by Chan and Sigafos (2000) in a comprehensive review of the literature. Challenging behaviour, for example, appeared to be a significant factor related to the use of respite care. The lack of communication skills is another factor to consider. Both challenging behaviours and lack of communication skills are possible contributing factors to the increased level of care required that might have contributed to the need for long-term respite care. The majority of the individuals in the study required a high level of care. Perhaps these characteristics contributed to increased care demands and levels of stress, which in turn made it difficult for families to provide care for their adult child at home? As a result, these individuals

remained in respite care. This interpretation is consistent with the fact that much of the required care fell upon a single parent. Single parents are more likely to seek respite care (Hoare et al., 1998) and once the child is placed outside the home, there may be a tendency for some parents to continue to rely upon that placement on a long-term basis.

The results of the present study should be interpreted with caution for several reasons. First, the study was based on a small sample of only 10 individuals. In addition these individuals came from one area of Sydney and may not be representative of other regions. As a result, the external validity of the study is limited. This limitation may be particularly relevant to this type of research because the results are likely to reflect the idiosyncratic policies and practices of a particular service. Second, there was no comparison group and so it is unclear if the results from this audit are similar to or different from what might be expected by chance. Third, direct interviews with the families concerned might have contributed more information to the study than an audit of case files alone. Fourth, a control group of adults with intellectual disability living in family homes who do not use long-term respite might have confirmed the proposed family indicators of respite use. Despite these limitations, the findings are consistent with the general trends identified in research literature (Chan & Sigafos, 2000).

It is interesting to note that while there were attempts to locate appropriate respite services for the individuals in the sample, there appeared to be no long-term placement plans for these individuals. In an effort to prevent unintended long-term use of respite care, it may be beneficial to undertake some proactive respite planning with families. The result of this audit suggests that this would seem especially useful for older single-parent families who have adult children with high support needs, challenging behaviour, and severe communication impairment. The study also suggests the need to adequately implement effective behaviour management and communication strategies (e.g., the use of appropriate augmentative communication systems) that might reduce the level of dependency on the families caring for these individuals.

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