

THERAPEUTIC AND SUPPORT SERVICES PROVISION FOR
CHILDREN WITH DUAL INTELLECTUAL DISABILITY
AND EMOTIONAL AND/OR BEHAVIOURAL
DIFFICULTIES IN CHRISTCHURCH, NEW ZEALAND

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Abstract

Therapeutic and support services provision for children with dual intellectual disability and emotional and/or behavioural difficulties was evaluated in the present study. The participants were parents of children with dual disabilities, aged between 5 and 12 and attending mainstream schools in Christchurch, New Zealand, and managers of service providers for the target group. Parents and service managers partook in semi-structured interviews designed to obtain information about patterns of service provision. The results of the present study indicate that parents and managers had similar perceptions of the extent to which services in Christchurch currently met the needs of the target children and families. Additionally, the study functioned as a pilot of the design and methods for a potential future project; therefore parent participants also completed two checklists estimating their child's adaptive functioning and the type and severity of their emotional and/or behavioural difficulties.

Position of the Researcher

I come to this research project with an interest in the lives of children with an intellectual disability and their families, particularly when dual emotional and/or behavioural difficulties are also present. While I have no direct family members who experience an intellectual disability, I have developed my interest over a number of years through both academic study, personal and work experience. The present research project is an extension of my interest through which I hope to gain further understanding of life when one is marginalised by a society that creates barriers. The way to obtain this is to follow what those with disabilities have advocated both informally and formally through the literature. That is to ask about lived experiences of children and families accessing the therapeutic and support services available within their community.

Chapter 1. Introduction

Well, you don't know where to ask for help. You don't get a manual when your child's born is to umm, or when she goes into school as to what's available [...] you're only told certain things and it's, and you don't know, I mean I've never had a child before, let alone one with a disability and I don't know the questions to ask. I don't know what, what is actually available out there and that, it makes it quite hard and quite frustrating. (Family Five)

Children with intellectual disabilities are more likely to experience emotional and behavioural difficulties compared to children without developmental delay (Dekker, Koot, & Verhulst, 2002). Co-occurrence of intellectual disability and clinically significant emotional and behavioural difficulties is commonly referred to in the literature as 'dual disability'. Utilising various measures, researchers have estimated prevalence rates of dual disabilities with results ranging from 30% to 60% in school aged children with intellectual disability (Dekker, Koot, & Verhulst, 2002). Emotional and behavioural difficulties in children with intellectual disabilities have been found to accompany a greater degree of impairment than those for children without intellectual disability (Dekker & Koot, 2003). Due to this, prior research has indicated that provision of community therapeutic and support services is likely to be important for such children and their families (Einfeld & Tonge, 1996a; Einfeld & Tonge, 1996b). Before reviewing the literature pertaining to provision and evaluation of therapeutic and support services, it is pertinent to outline how intellectual disability and emotional and behavioural/mental health difficulties are currently conceptualised and examine the factors which may contribute to the development and maintenance of dual disabilities.

Intellectual Disability

Defining ‘intellectual disability’ requires consideration of the various means of conceptualisation currently used for both research and clinical purposes. This section will describe two of the most frequently employed conceptualisations of intellectual disability and justify the definition and classification criteria that were applied to define ‘intellectual disability’ in the current research project.

Changing models of disability have influenced how intellectual disability and developmental delay are conceptualised. With increased awareness of the dual influence of both internal and environmental factors, defining intellectual disability for clinical and research purposes requires implementation of a reliable and valid system of classification that distinguishes between those with and without cognitive impairments and adaptive functioning difficulties. Currently in New Zealand, the criteria that inform this decision are predominantly based upon those outlined in the Diagnostic and Statistical Manual of Mental Disorders 4th Edition – Text Revision (DSM-IV- TR) (American Psychiatric Association, 2000). The most commonly used term to describe such difficulties in New Zealand is ‘intellectual disability’, which is synonymous with a diagnosis of Mental Retardation in the Diagnostic and Statistical Manual of Mental Disorders 4th Edition – Text Revision (DSM-IV- TR) (American Psychiatric Association, 2000). The term ‘mental retardation’ is also used in the tenth edition of the manual published by the American Association on Mental Retardation (AAMR) (Luckasson et al., 2002). While the DSM-IV criteria will guide the definition of intellectual disability in the present study, the World Health Organisation has developed a system for the classification of intellectual disability which is worth considering in further detail.

The International Classification of Functioning, Disability and Health (ICF) (World Health Organisation, 2007) was developed to provide a standard international language and framework for conceptualising disability. It was designed to correspond with the International Classification of Diseases (WHO, 1992; 1993; 1996), more commonly referred to as the ICD 10 (Carr & O'Reilly, 2007). The foundation for the ICF is the 'Biopsychosocial' model, which considers multiple inter-related factors as the basis for an individual's level of functioning and disability (Carr & O'Reilly, 2007; World Health Organisation, 2002). Classification of disability according to the ICF involves the integration of two components; (1) Functioning and disability and (2) Contextual Factors (World Health Organisation, 2002). Body functions and structures and activities and participation are considered under component one and environmental and personal factors under component two (World Health Organisation, 2002). Disability is used as an umbrella term to describe impairments, activity limitations and participation (World Health Organisation, 2002). Each of these factors is considered to contribute to the level of disablement experienced by the individual. While the ICF model is frequently cited as the basis for defining disability, it has not yet been universally adopted in New Zealand or elsewhere. Therefore, the DSM-IV-TR (2000) classification which is most commonly adopted will be utilised for the purposes of the current research and is described in further detail.

A diagnosis of Intellectual Disability is made on Axis 2 of the DSM-IV-TR (2000) and impairments must meet three criteria. Firstly, cognitive assessment must indicate intellectual functioning is below average with an intelligence quotient (IQ) score of less than 70, which is classified as two standard deviations below the mean population score. Secondly adaptive functioning ability must be impaired in two or more of the following areas; communication, self-

care, home living, social/interpersonal skills, use of community resources, self-direction, functional academic skills, work, leisure, and health and safety. Similarly impairment is classified as two standard deviations below the mean population score. Thirdly, onset must occur before the age of eighteen. The DSM-IV-TR (2000) utilises five different codes that reflect the level of severity of the intellectual disability. Mental Retardation is coded as Mild when the IQ level is 50-55 to approx 70, Moderate when it is 35-40 to 50-55, Severe when it is 20-25 to 35-40 and Profound when the IQ level is below 20-25. It may also be coded as Severity Unspecified when there is suspicion of impaired cognitive functioning but this is unable to be tested psychometrically.

As indicated above, the terminology utilised to describe cognitive or developmental delay is different depending on a number of factors. These include the method of classification applied, the country, what has been commonly utilised in the past and the requests of consumer groups. People First consumer groups have been influential in determining the terminology utilised to describe and classify cognitive difficulty. As a result, in the United Kingdom and more recently New Zealand, the term 'Learning Disability' has increasingly replaced the term 'Intellectual Disability' to describe people who have deficits in intellectual functioning. This change in terminology is relatively new and presents some complications when utilised with the DSM-IV-TR (2000) classification system because of the requirement to determine differential disabilities. An important difficulty to recognise is the possibility for confusion between Mental Retardation and the various 'Learning Disorders' outlined in the DSM. Given that the term 'intellectual disability' is currently the most widely utilised in New Zealand literature and the possibility for confusion when utilising the term learning disability with the DSM-IV-TR (2000) classification,

the term 'intellectual disability' will be employed interchangeably with 'developmental delay' in the present dissertation.

Emotional and Behavioural Difficulties

Children with intellectual disabilities are more likely than children without developmental delay to present with emotional and behavioural difficulties (Dykens, 2000). Tonge (1999) indicated that emotional and behavioural difficulties occur approximately three times more often in this population than among children at large, which reflects the findings of earlier research by Michael Rutter, Thomas O'Connor and the Romanian adoption study team. A number of studies have identified that children with intellectual disabilities may present with the following difficulties; anxiety and mood disorders, disruptive behaviour disorders such as attention deficit hyperactivity disorder, stereotypies or self-injurious behaviours, psychosis, communication impairment and feeding and elimination disorders (Dekker, Koot, & Verhulst, 2002; Dekker & Koot, 2003; Dykens, 2000; Hardan & Sahl, 1997). The types of emotional and behavioural difficulties displayed by children with intellectual disability have generally been found to be related to the level of severity of the cognitive impairment however various studies have identified differing patterns. An Australian prevalence study found that children with mild intellectual disabilities had higher scores on behavioural dimensions (Einfeld & Tonge, 1996b). Mood and anxiety disorders are more likely to be found in children with mild and moderate levels of intellectual ability, whilst behaviour disorders such as self injury are more common in severe cases of intellectual disability (Dykens, 2000).

Recognition of emotional and behavioural difficulties displayed by children with intellectual disabilities typically relies on both parents and professionals (Paschos & Bouras, 2007). Parents are most likely to be the first to notice the changes in behaviour which they may then report to a medical, educational or mental health professional who can conduct assessment (Zwaanstijk, Verhaak, Bensing, Ende van der, & Verhulst, 2003). Agreement amongst such professionals on appropriate best practice methods of classification is elusive. Particularly because the patterns of difficulty displayed by children with developmental disability do not necessarily reflect those outlined in the classification systems (Tonge, 1999). In New Zealand, difficulties are typically diagnosed according to DSM-IV-TR (2000) criteria utilising various measures and clinical judgement to evaluate symptomatology. There are however, a number of issues with this method of classification and these will be identified and discussed further in later chapters.

Risk Factors for Dual Disabilities

Multiple biological and environmental factors may contribute to higher levels of emotional and behavioural difficulties among children with intellectual disability. Dykens (2000) separates environmental factors into three groups; psychological factors intrinsic to the individual, familial factors and wider social issues. Biological factors include not only genetic vulnerabilities but also physical health difficulties such as seizure disorders and sensory impairments. Numerous variables have been found to mediate the pathways between each of these areas of risk and psychopathology.

According to the DSM-IV (1994) classification criteria, Dekker and Koot (2003) identified negative life events, parental psychopathology and parental referral to mental health care as the strongest predictors for diagnoses of emotional and behavioural difficulties in children with intellectual disabilities. More recently Koskentausta et al. (2007) summarised approximately thirty years of research on risk factors and identified the following as the most common mediating variables identified in the available research; male gender, increasing age, low socio-economic status, living in a single parent household, lower intelligence level score, less opportunity for socialisation, daily functional skill deficits including communication difficulties, epilepsy and unaffected mobility. Unfortunately however, much of the evidence for these is insufficient and conflicting due to methodological variability (Paschos & Bouras, 2007). Koskentausta et al. (2007) utilised four questionnaires to further clarify risk factors. The results obtained from the sample of children from six to thirteen years old identified a moderate level of intellectual disability, adaptive functioning difficulties, impaired language development, single parent co-habitation and low socioeconomic status as the most significant risk factors for psychopathology.

Examination of the risk factors for emotional and/or behavioural difficulties just presented indicates that most apply not just to children with intellectual disabilities, but also to children at large. Prevalence research has indicated however, that children with intellectual disabilities present with such difficulties at higher rates. The possible reasons for this occurrence therefore require consideration, particularly the specific features associated with intellectual disability that may have an impact. While all children with intellectual disabilities share the common characteristics of impaired IQ level and adaptive functioning, the causal mechanisms

are diverse and disability is not homogenous. In at least half of cases, the cause of intellectual disability may actually be unknown (McDermott, Durkin, Schupf, & Stein, 2004).

Where the etiology of an intellectual disability is known, it could be linked to numerous occurrences such as genetic abnormalities, birth trauma, teratogenic and neurotoxic chemicals, injuries and deprivation. Symptoms of emotional and behavioural difficulties have been linked to specific syndromes characterised by impaired intellectual ability. Children with Down syndrome, for example, may display noncompliant, stubborn, inattentive, over-active and withdrawn behaviours. Children with Fragile X syndrome on the other hand, are more likely to display social anxiety, perseveration, sadness and depression (Dykens, 2000). As a result of the recent advances in genetics researchers have been able to study differences in genotype and phenotype between syndromes. Dykens and Hodapp (2001) review recent findings, for example, citing the presence of different levels of the cerebral spinal fluid oxytocin in people with Prader-Willi syndrome which is thought to be associated with the obsessive and compulsive behaviours more frequently observed in this syndrome.

Moving beyond causes of intellectual disability, psychological, familial, social and biological factors have been found to mediate the link between intellectual disability and emotional and/or behavioural difficulties (Dykens, 2000). The well-regarded Romanian adoption studies conducted by Michael Rutter, Thomas O'Connor and colleagues have demonstrated that there are both genetic and environmental conditions that affect the development of dual disabilities. The studies with Romanian adoptees indicate that children's development of intellectual and emotional and/or behavioural difficulties is influenced by aversive environmental factors such as poverty and deprivation (Croft et al., 2001). The introduction of adaptive

environments and positive caregiving experiences was found to decrease the extent of the children's cognitive delays and emotional and/or behavioural difficulties. However the extent of improvement appears to be dependent on the length of deprivation, with more severe levels of difficulty remaining for children who had sustained deprivation for longer periods of time (Croft et al., 2001). Even where initially adaptive environments are provided for the child, internal psychological factors linked to intellectual disability have been found to affect the caregiving relationship and therefore subsequent development of emotional and/or behavioural difficulties. Children may have aberrant personality styles which could result in over-dependency or withdrawal for example (Dykens & Hodapp, 2001). Furthermore, due to developmental delays the capacity for such children to engage in adaptive attachment experiences with primary caregivers may be negatively affected (Al-Yagon, 2007). Physical health disabilities could also potentially influence the development of emotional and/or behavioural difficulties in children with intellectual disabilities. The rate of epilepsy is significantly higher in the population of children with intellectual disabilities (Deb, 2004). Epilepsy has major effects on brain functioning, including behavioural and emotional outcomes, therefore it can be considered a biological risk factor (Deb, 2004).

As this somewhat inadequate discussion of risk factors for emotional and/or behavioural difficulties in children with intellectual disabilities has indicated, knowledge of the reasons for their increased prevalence is currently advancing. Explicit in the conclusions of research studies is the argument for provision of efficacious therapeutic and community support services to children with dual disabilities and their families. Such a recommendation is further reflected in the research literature and outcome measures to determine the extent to which services are

meeting community needs have been proposed (Park et al., 2003). However the availability and quality of such services currently depends upon various factors which first require consideration.

Impact of Therapeutic and Support Services

Children with dual disabilities and their families are generally considered to require therapeutic and support services at an intensity greater than those with one or no such difficulties (Park et al., 2003; Scior & Grierson, 2004). The impact of not receiving such support on the child, parents and family system can manifest in a number of detrimental ways, particularly over time when services for early intervention have not been available or utilised (Herring et al., 2006).

Outcomes that are associated with caring for a child with either an intellectual disability, mental health difficulty or both include high levels of parental stress, parental mental health difficulties and dysfunctional family systems (Hastings, 2002; Herring et al., 2006). A higher level of severity of both intellectual disability and emotional and/or behavioural difficulties has been associated with a greater perceived burden of care by parents, and increased need for provision of therapeutic and support services (Haveman, van Berkum, Reijnders, & Heller, 1997).

There appears to be a bidirectional relationship between parental stress and child behavioural difficulties (Herring et al., 2006). Research in this area has implicated that personal and social factors associated with both the child and their parent can serve to either increase or decrease the level of stress and behavioural problems (Keller & Sterling-Honig, 2004; Turnbull & Ruef, 1996). Turnbull and Ruef (1996) found that one of the most important needs identified by families was the provision of ‘multi-component’ support with one area of emphasis being on de-escalating stress levels. Keller and Sterling-Honig (2004) indicated that having a child with

dual disabilities is liable to induce greater stress as a result of their care needs and behaviour, however the extent to which this negatively impacts on the family is mediated by the parents' coping mechanisms as well as interpersonal and environmental factors. Furthermore, in relation to family functioning, an ecological view of the family system is essential when considering the provision of therapeutic and support services to families.

While high levels of stress and family dysfunction are more likely to occur in families who care for a child with a dual disability, this does not necessarily generalise to individual family circumstances. The concepts of risk and resilience are implicated in this regard, because personal and environmental variables that are unique to the family situation are likely to determine the resources on which they are able to draw for support (Koskentausta, Iivanainen, & Almquist, 2007). Furthermore, how a family perceives their situation is likely to determine the support services which they are able to access (Gallagher & Floyd, 1997; Turnbull & Rief, 1996). In other words, a family's experience of dual disability is subjective in that it is reliant upon their understanding of the nature and extent of their child's difficulties, and their knowledge about how to access support services, as well as the national and local support service structures available in their community.

Summary

Having discussed how intellectual disability and emotional and behavioural difficulties will be conceptualised in the current study, and determining the pertinent risk factors for the occurrence of dual disabilities, this section discussed the potential impact of service provision on the child and their family. It is now pertinent to consider how therapeutic and support services have been

provided and evaluated both nationally and internationally. This is the aim of the next chapter, at the conclusion of which the purpose of the current study will be outlined and the research questions and aims presented.

Chapter 2. Therapeutic and Support Services Provision and Evaluation: a Review of the Literature

While there is a significant body of research focused on the assessment of emotional and behavioural difficulties displayed by children with intellectual disabilities, there is little focused on the identification and evaluation of therapeutic and support services provision for this group. The present section will review the body of research literature available from both New Zealand and overseas studies that pertains to evaluation of therapeutic and support services provision and evaluation for the target group. The review will be presented in separate sections addressing disability models, involvement of children and families in service evaluation, international trends in support service provision for the target population, and the structure of therapeutic and support services in New Zealand. The inclusion and exclusion criteria that determined which studies would be discussed in the following review are outlined first.

Inclusion and Exclusion Criteria

A series of library and database searches were carried out by the researcher with a view to locating the most comprehensive set of relevant literature. The University of Canterbury Library was utilised to search the catalogue for book based resources and to access databases, journals and articles. Databases accessed through the University of Canterbury library were Proquest 5000, MedLine and PsycINFO. The Google Scholar search engine was utilised most frequently as it enabled comprehensive access to a wider range of materials than a single database. The search key words most commonly included but were not limited to: services, support, provision,

mental health, emotional difficulties, behavioural difficulties, intellectual disability, learning disability, mental retardation, dual diagnosis, dual disability, family, child and parents. To access all forms of each keyword, truncation operators were utilised. In an attempt to ensure that the literature obtained was as comprehensive as possible the reference lists for each article were consulted for potentially relevant earlier references. Recent and key articles as well as reviews were used to locate further relevant articles. Only research published in the 15 years from 1992 to 2007 is included. Participants must be either children with both intellectual disabilities and emotional and behavioural difficulties or their parents or professionals involved in service provision for such children. While the focus is on children in the current dissertation, due to the small body of research available the literature search also accessed evaluations of adolescent and adult dual disability services.

Disability Models

Disability models were briefly discussed earlier in relation to the conceptualisation of intellectual disability however it is important to also consider how they may influence the provision and evaluation of services. Aspects of both the medical and social models of disability currently influence therapeutic and support services for people with dual intellectual disability and emotional and behavioural difficulties (Bouras & Jacobson, 2002; Williams & Heslop, 2005).

The extent to which each model is reflected in provision of services is generally dependent upon a number of variables including both structural organisational factors and staff attitudes and practices (Williams & Heslop, 2005). Organisational factors include whether or not the service is provided through a ministry under the umbrella of the government and the design of the policies

that guide governance of the organisation as a whole. Practice guidelines and staff interest in dual disability are also guided by disability models. Furthermore, attitudes towards disability and people with disabilities are thought to have a significant impact (Neilson, 2005).

Internationally researchers have worked with people who have experienced mental health difficulties to develop an understanding of consumer perceptions of mental health services. The results have indicated that assessment and intervention based on the medical model is liable to disregard complex life experiences and important environmental and individual factors (Faulkner and Layzell, 2000, cited in Williams & Heslop, 2005). As a result a social model of mental distress has emerged which engages “more fully with the inner worlds and lived experiences of individuals, as well as with external social, economic and environmental factors, making a direct link between these two worlds” (Williams & Heslop, 2005). The model does not discount the potential efficacy of medical treatment, it does however advocate for a broader understanding of emotional and behavioural difficulties as extensions of intolerable life circumstances (Williams & Heslop, 2005). Currently, the model has not been widely adopted outside of the United Kingdom and the majority of intellectual disability and mental health services in developed countries still have not achieved the balance between the medical and social models of mental distress which Williams and Heslop (2005) describe as optimal.

Traditionally intellectual disability and mental health services in New Zealand have been based upon medical model of health and disability (Molony, 1993). Government funded intellectual disability and mental health services have generally been included with general health services which were predominantly based upon biomedical models of care, particularly inpatient and outpatient hospital settings (Gawith & Abrams, 2006). The medical model views

disability, including mental health disability, as largely an ‘individual’s’ difficulty and therefore treatment is typically aimed at improving ‘symptoms’. As a result professional approaches and services are characterised by practice guidelines where the outcomes are focused on making the human mind and body as ‘normal’ as possible (Kirk, 2006). The shortcomings of the medical model have been increasingly recognised and subsequently reflected in changing support structures for people with dual disabilities, such as deinstitutionalisation and assertion of equal rights (Molony, 1993).

As a component of its response to advances from the medical to social model of disability, the New Zealand government has expended a relatively significant quantity of resources aiming to improve intellectual disability and mental health services. Large research projects have been commissioned such as the Quality and Safety Project by the Ministry of Health in 2004. A component of this project was focused on the disability support sector, in particular service users perceptions of the services provided to them. Similarly The Like Minds Like Mine Plan (Bishop, 2007) was set up in 1998 to counter discriminatory attitudes in New Zealand. In accordance with the social model of disability, the plan recognised that people with disabilities were systematically excluded from society due to discriminatory attitudes, values and beliefs (Gawith & Abrams, 2006). Influences of the social model have become increasingly recognisable in disability services however there remains significant progress to be made through research with consumers and providers, especially in the area of services for children, young people and their families.

Involvement of Children and Families in Service Evaluation

The quality of information which children with dual disabilities and their families can provide regarding accessing and utilising therapeutic and support services, is likely to be most accurately obtained by asking about and listening to their lived experience (Russell, 2004). This type of approach is central to the practice of the social model of disability (Ballard, 1994). While parents are becoming increasingly involved in the process of disability research, there remains a significant proportion of academics who do not yet value enough the outcomes of such research ventures (Carpenter, 2000). As a result articles have been published which further emphasise the importance of engaging in not just research on disability, but qualitative research in partnership with families that will have a positive outcome.

Russell (2004) reports on the utilisation of a parent partnership research model in the doctoral thesis she completed, which aimed to gather and evaluate parents perspectives on the services provided during their child's transition from early childhood to primary education in the United Kingdom. The author identified this approach as a key component of qualitative research in the child disability field. Parents are frequently the key advocates for their child's wellbeing and "although parents do not have impairments themselves, they can be subject to the disabling barriers and attitudes of the professional world and in the wider community when acting on behalf of their disabled child" (Russell, 2004, p. 76). Therefore, the research project involved parents in the roles of both researcher and participant with consultation occurring at each stage. Semi-structured interviews were conducted with parents to ask about the services provided to their family. The transcripts were analysed using a thematic coding process to identify not only common themes but differences in individual experiences of services. Russell (2004) concluded

that utilising a participatory approach enabled parents to have a greater degree of control over the process and findings of the research therefore enriching the outcomes for the families of children with disabilities involved in the study. Increasingly researchers are recognising the need for research with, rather than on children with dual disabilities and their families. In relation to provision of therapeutic and support services, such research outcomes can be utilised in the evolution of service structures that more closely reflect the identified needs of families.

International Trends in Support Service Provision for Target Population

International studies have evaluated trends in therapeutic and support services provision for children and young people with dual intellectual disability and behavioural and/or emotional difficulties. They have gathered information about both the structure and content of services as well as evaluations of how the services are meeting the needs of service users and their families, however predictably there remains significant variation between developed countries (Koskentausta, Iivanainen, & Almquist, 2007). Included in this part of the review are those studies that directly relate to these topics. Due to the small number of studies that have been conducted in this field, the demographic characteristics of the target populations are wider than that specified for the current study.

Research focused on assessment of emotional and/or behavioural difficulties in children often concludes that children with dual disabilities and their families will require support services at a greater level and intensity than most families. For example Einfeld et al. (2006) published a report on their longitudinal Australian Child to Adult Development Study which has tracked the course of emotional and behavioural difficulties over time. The authors found that

emotional and/or behavioural difficulties are both stable and persistent. This predicates the need for effective interventions to ensure such children enjoy adequate quality of life. A similar conclusion was reached by Koskentausta et al. (2007) who examined risk factors for psychopathology in children with intellectual disability utilising data from case files and four parent informant questionnaires including the Developmental Behaviour Checklist. Studies such as these provide a rationale for the provision of therapeutic and support services to the target population. However, the extent to which such services are utilised is also an important consideration.

An essential element of service evaluation on a large scale is to determine the populations who have the highest need so that services can be provided as in the most efficacious manner possible (Einfeld & Tonge, 1996a). Einfeld and Tonge (1996a & 1996b) conducted a study with this aim which investigated the prevalence of emotional and behavioural difficulties in a representative sample of Australian children between four and eighteen with an intelligence quotient below 70. Utilising the Developmental Behaviour Checklist as a measure of emotional and behavioural difficulties they identified that of their sample of children with previously identified intellectual disability, 40.7% had severe emotional and behavioural difficulties which may classify as a psychiatric disorder. Furthermore, less than 10% of that group had received therapeutic and support services.

Douma, Dekker & Koot (2006) conducted a similar study in the Netherlands but also asked parents of children and young people about their perceptions of the support they need and the extent to which such needs are being met. To do this the authors developed a questionnaire called the 'Need for Help Questionnaire'. Questionnaire items were developed after

consideration of the literature as well as the answers given by parents and service providers in a series of semi-structured interviews. The questionnaire asked about parent's needs for support, where they obtained such support and why they did not seek support when it was available. Employing quantitative methods of data analysis the authors found that over 88% of parents with children who have dual intellectual and emotional and behavioural difficulties required some type of support. They also asked about which types of support were most important and found that 'a friendly ear', 'information' and 'child mental health care' were those most often needed. There was significant variation among parents regarding what types of support were needed. However, formal supports such as mental health care tended to be sought only in the second instance after informal supports were found to be inadequate. When asked why they had not sought help, parents most frequently said that they didn't believe the problems were serious or pervasive enough to warrant help, that they thought they could solve the problem themselves and a lack of knowledge of where to seek help in the first place or even where such information could be found. The report concluded with a suggestion that each child should be assigned a case manager who would serve as the first contact for parents and function as a mediator between parents and service providers.

Focusing on children with dual behaviour difficulties and intellectual disability, McGill and colleagues asked 66 families to complete questionnaires about the type of professional service they had received, their satisfaction with that service and whether or not it had been helpful (McGill, Papachristoforou, & Cooper, 2006). Similar to the studies described above, they found that overall families were dissatisfied with the therapeutic and support services they had received. They concluded that the families who participated often perceived services as

unhelpful and those services that they did receive were often ill matched to their needs.

Furthermore the interventions were not consistently evidence based. In order to provide services that more accurately reflect the needs of families they suggested that research should more proactively seek information from families.

Both of the studies above utilised questionnaires as a data gathering tool. While questionnaires have the potential to gather accurate information from many participants, the amount of information is generally limited by the fact that participants are required to articulate their thoughts in a written form (Wilkinson, Joffe, & Yardley, 2004). An alternative to a questionnaire is a structured or semi-structured interview conducted with a smaller sample size. This has been utilised in a small number of studies focused on evaluating services for the target population. An older study by Turnbull and Ruef (1996) interviewed seventeen families of children with dual intellectual and behaviour difficulties. The goal of the interview, which was conducted over the phone, was to encourage family members to talk about their perspective of the disruptive behaviour displayed by their children, challenges their family experiences, successful approaches they utilise and what type of information would be most helpful for them to lessen the impact of disruptive behaviour. The answers obtained indicated that functional assessment to determine the reason for the behaviour, and multi-component support that comprehensively addresses difficulties in all relevant environments, were considered to be important aspects of service provision. Access to informational resources was an additional area which the authors identified as lacking.

Williams and Heslop (2005) reported on research conducted with young people who have dual intellectual and emotional and behavioural difficulties which aimed to gain information

through interview methods. The study obtained information about what the young people and their families articulated about how support needs could best be met during a time of transition. The aim of this study was to improve and extend the services that were already available to the target population. The results indicated that the participants wanted support that was person-centred and individualised. Overall the authors concluded that there are a number of barriers to support, and there is a requirement that they are systematically addressed so that people are able to access a clear network of agencies through well articulated referral routes.

Generating understanding about the experience of parents with children with dual disabilities, including the impact of seeking support from services, was the aim of a study by Faust and Scior (2007). Semi-structured interviews were conducted with parents of young people aged 16 to 25 and an Interpretative Phenomenological Analysis of the transcripts indicated that the impact of dual intellectual disabilities and mental health difficulties on parents is pervasive. Perceptions of service provision were generally negative with parents describing feelings of isolation, confusion and the sentiment that services were not attuned to the needs associated with their personal family circumstances. In a previous study by one of the same authors, a selection of senior service providers were interviewed to explore their experiences of working with children with dual disabilities and evaluate their views on how the services are meeting the needs of the target group. Scior and Grierson (2004) concluded that service providers perceived a gap between the policies which are meant to guide therapeutic and support services provision for this group and the reality of what actually occurs. The authors advocated for improved multidisciplinary and multi-agency links as a result of findings which suggested that these were currently not optimally present.

The studies described were all conducted outside of New Zealand and did not specifically address therapeutic and support services provision for the group which will be targeted in the current study. While all were related to children and young people, many were conducted in settings that are not sufficiently comparable to service provision patterns in New Zealand. As a component of a literature review focused on evaluating specific interventions with children with developmental delay displaying challenging behaviour, Meyer and Evans (2006) articulated some research-based opinions relating to service provision in New Zealand. In particular, a holistic view of the family and its environment was considered to be best practice, particularly in light of its affinity with Maori models of health and wellbeing. The authors also acknowledged that there are a variety of factors which are considered when decisions about what and how supports will be provided. As well as their evidence base, supports are also judged on their cost, availability and acceptability within social values, including cultural considerations. An evaluation of the therapeutic and support services which have the potential to provide the interventions addressed was not within the scope of the literature review by Meyer and Evans (2006). Such research was not found during the relatively extensive literature searches conducted for this review therefore justifying the topic of the current research.

Structure of Therapeutic and Support Services in New Zealand

The following section outlines what is known to the researcher about the therapeutic and support services available for children with dual intellectual disability and emotional and/or behavioural difficulties in New Zealand prior to completing data collection and analysis. The purpose here is only to give the reader a preliminary framework addressing the basic structure and functions of

therapeutic and support services in New Zealand for children with dual intellectual disability and emotional and/or behavioural difficulties.

The guiding strategy for all governmental disability services is The New Zealand Disability Strategy: Making a World of Difference Whakanui Oranga (Dalziel, 2001). The strategy, which was published in 2001 by the Minister of Disability Issues, aims to eliminate societal barriers and promote an inclusive society at a governmental policy and procedure level. In order to achieve this aim the strategy set out 15 broad *Objectives* supported by detailed *Actions* that should occur. Relevant governmental departments were then required to develop and implement a work plan to ensure that the objectives are met over a period of years. The objectives all relate to service provision for children with dual disability however those that are probably most directly relevant are ‘Objective 2: Ensure rights for disabled people’, ‘Objective 3: Provide the best education for disabled people’, ‘Objective 7: Create long-term support systems centred on the individual’, ‘Objective 8: Support quality living in the community for disabled people’, ‘Objective 10: Collect and use relevant information about disabled people and disability issues’ and ‘Objective 13: Enable disabled children and youth to lead full and active lives’. These objectives should guide practice provided by therapeutic and support services for children with a dual disability.

The Disability Strategy is based on the current social model of disability mentioned earlier in this chapter in that it advocates for societal change in their perception of and response to people with intellectual disabilities in their community. The summary of the strategy states that;

Disability is not something that individuals have. What individuals have are impairments. They may be physical, sensory, neurological, psychiatric,

intellectual or other impairments. Disability is the process which happens when one group of people create barriers by designing a world only for their way of living, taking no account of the impairments other people have (Dalziel, 2001, p. 1).

The strategy sets out a number of outcomes which the New Zealand government is committed to achieving and services that are run under the government umbrella are required to provide their services in accordance. Therapeutic and support services are provided to children with dual disabilities from a number of different government ministries including health, social development and education.

The Ministry of Health oversees provision health and disability services however responsibility for provision and funding of therapeutic and support services lies with local District Health Boards (DHBs) and private or non-governmental organisations (Ministry of Health, 2007). The New Zealand Disability Strategy described above is one of two guiding strategies for the Ministry of Health, the other is the New Zealand Health Strategy. Physical health requirements of children with dual disabilities are predominantly provided community Primary Health Care agencies and professionals such as general practitioners (Ministry of Health, 2007). Inpatient and outpatient hospital services, as well as some community based services are overseen by DHBs. Mainstream mental health and intellectual disability services are also separately administered by DHBs within the hospital system. Needs Assessment Co-ordination Agencies (NASC) are contracted by each DHB to assess and determine the therapeutic and support services needs for people with disabilities (IHC/IDEA, 2006). It covers “physical, intellectual, developmental, and medical needs” (IHC/IDEA, 2006, p. 1) and takes into account social needs as well as family circumstances. This assessment can be requested by any person involved in the care of the child with dual disabilities but it does not occur unless

asked for. Children with dual disabilities are most commonly referred to public physical and mental health services through a needs assessment however there are exceptions due to individual circumstances. Overall, the health and disability needs of children with dual disabilities are provided by a combination of governmental, private and non-governmental organisations.

The Ministry of Education provides educational support to children with dual disabilities through the Group Special Education service. Group Special Education is structured at a national, regional and district level and provides services to “children and young people with high and very high educational, social, behavioural, and communication needs” (Ministry of Education, 2007). Direct services are administered at the district level to children from birth to school leaving age by a variety of professionals such as psychologists, speech language therapists, occupational therapists, physiotherapists and support workers. Assessment and allocation of funding for educational provision in mainstream schools for children with dual disability is guided by the Special Education 2000 scheme. Funding is administered through Ongoing and Reviewable Resourcing Schemes (ORRS) and the School High Health Needs Fund (SHHNF) as well as a Special Education Grant to schools. As a government organisation the Ministry of Education is also committed to achieving the objectives set out in the New Zealand Disability Strategy.

The Ministry of Social Development and its constituent parts, such as Work and Income New Zealand (WINZ), may also be involved with service provision for target population, particularly in regard to funding and allowances. If there are concerns related to family

functioning and/or child maltreatment, Child, Youth and Family may be involved to provide support to parents or alternative care arrangements.

Non-governmental agencies are also commonly involved in provision of services to children with dual disabilities across health, education and welfare. Children will generally have access to a General Practitioner to varying extents. Some general practices are funded through the government as Primary Health Organisations (PHO's) however others remain private. IHC and its constituents, IDEA (Intellectual Disability Empowerment in Action), Family/Whanau Services and Timata Hou, are perhaps the most widely known providers of services to children as well as adults with intellectual disabilities in general however there are a number of smaller agencies. Those agencies may provide any number of services however they often have a focus such as respite care, consumer advocacy or a specific type of intellectual disability or emotional and behavioural difficulty. Services are also available for parents and siblings, particularly support groups which may enable parents to network with other parents who have children with similar difficulties and with relevant professionals. Recreational support groups are also common and often provide a forum for families with children with common disabilities to meet and share knowledge and expertise.

Purpose of the Current Study

With this brief overview of the potential therapeutic and support structures available to children with dual intellectual and emotional and/or behavioural difficulties and their families in New Zealand in mind, the question of whether such services are accessible and meeting the needs of the target population remains to be evaluated. While many studies have written concluding

comments that children with dual disabilities and their families require community therapeutic and support services to a greater extent than those who do not have such difficulties, it appears that there is little research evaluating how such services are being administered in New Zealand and whether they are perceived to meet the needs of consumers. Personal communications with those involved in service provision for this group of children have indicated that in fact, many children with dual disabilities “fall through the gaps” for a number of reasons. Misunderstanding between services about who is responsible for provision and exclusionary eligibility criteria are just two reasons that were identified. Additionally, limited resources including both funding and staff shortages have been implicated in difficulties providing services to children experiencing dual disabilities and their families.

These observations and a review of the literature just presented, highlighted to the researcher that there was a gap in knowledge about how access to and experience of support services may be related to the type and severity of dual disabilities. In particular, the patterns of therapeutic and support services seemed undefined and inconsistent for children with dual disabilities attending mainstream primary schools in Christchurch, New Zealand. Furthermore, understanding about how the type and severity of dual difficulties might influence the provision of services that meet the needs of consumers seemed elusive. With the aim of initiating an investigation into this field the following three research questions were developed;

1. What are the patterns of therapeutic and support services provision for children with dual intellectual disability and emotional and/or behavioural difficulties in Christchurch, New Zealand?

2. To what extent are the scale and nature of such services matched to the severity and type of children's intellectual disability and emotional and/or behavioural difficulties

3. To what extent are parent opinions about therapeutic and support services matched to the severity and type of children's intellectual and emotional and/or behavioural difficulties?

In order to evaluate these three research questions a mixed method design was proposed because it would enable a comprehensive data set to be collected and analysed. The literature reviewed indicated that quantitative measures would be required to accurately estimate the type and severity of the child's difficulties. However, the literature related to evaluation of disability support services which has been discussed in the previous review has indicated that parental opinions about support services can be most comprehensively evaluated using qualitative methods such as semi-structured interviews. Therefore, a study which was to accurately answer the research questions proposed above would not only require a sample size large enough to include a valid number of children, but also require interviews with both the parents and service providers for each child to gather information about the scale and nature of services provided. It was determined that this endeavour was beyond the scope of the present master's dissertation, particularly given the difficulties encountered during the participant recruitment process, but could perhaps be completed as a doctoral level study.

For the study proposed above to appropriately address the research questions outlined, a pilot of the proposed design and methods would be valuable. Furthermore, to enable an evaluation of the extent to which parent opinions match the type and severity of the child's difficulties, it would be advantageous to have an indication of how needs are currently being met from the perspective of both parents and service providers in Christchurch, New Zealand. These preliminary enquiries therefore inform the research aims which have been developed for the current research project. The aims are to:

1. Describe the patterns of therapeutic and support services provision for children with dual intellectual disability and emotional and/or behavioural difficulties in Christchurch, New Zealand.
2. Evaluate parent's perceptions of the services they are receiving and how they are, or are not, meeting their needs.
3. Evaluate service provider's perceptions of the services they provide, and how they are, or are not, meeting the needs of their consumers.
4. Evaluate the extent to which is there a convergence between parents' and service providers' perceptions of how therapeutic and support services are meeting the needs of children with dual disabilities.

5. Evaluate the extent to which the quantitative methods selected accurately describe the type and severity of difficulties, and the extent to which the semi-structured interview for parents accurately determines the level of support received and required.

Chapter 3. Method

Design

Given the nature of the initial research questions in which both quantitative and qualitative information was going to be sought, a mixed methods design was deemed most appropriate for the purposes of determining how the severity and type of dual disabilities may influence the services provided for children and families. Creswell, Plano-Clark, Gutmann and Hanson (2003) explain that mixed methods designs incorporate quantitative and qualitative data within “a single study in which the data are collected concurrently or sequentially, are given a priority, and involve the integration of that data at one or more stages in the process of research” (p. 212). Mixed method designs have been applied with increasing frequency in both educational and psychological research because of the breadth and depth of information gathering they facilitate (Kroll, Neri, & Miller, 2005; Mertens, 2005). The most appropriate quantitative and qualitative research data gathering procedures may be selected and utilised in a complementary manner to provide enriched information about the phenomenon of interest (Kroll, Neri, & Miller, 2005).

A mixed methods design typically consists of a ‘base method’ which guides the design of the research, particularly the selection of data collection and analysis strategies (Morse, 2003). Like purely quantitative and qualitative designs, mixed methods research approaches are also informed by epistemologies and theoretical perspectives which in turn determine both the methodology and the specific methods that are used to answer the research question (Creswell, 2003). The base method for the current research project is qualitative, with quantitative aspects

integrated to enable an efficient estimate of the type and severity of dual disability. The qualitative nature of the proposed design is informed by a phenomenological perspective.

Phenomenology

Phenomenological inquiry was chosen to guide the current research project because of its focus on the interpretation of the subjective lived experience of individuals (Chamberlain, Comic, & Yardley, 2004). Its original basis stems from the thinking of the philosopher, Kant, who wrote about systematic investigation of ‘phenomena’, which he considered to be conscious experiences consisting of structured content (Chamberlain, Comic, & Yardley, 2004). Philosophers continued to analyse human experience using a phenomenological framework and subsequently, it has been developed into a research method characterised by the analysis of subjective accounts of ‘lived experiences’ (Chamberlain, Comic, & Yardley, 2004; Creswell, 2003). The approach enables study of the accounts of a small number of participants to gain an in-depth understanding of their experience (Creswell, 2003). The outcome is not an objective statement of the phenomenon itself but an account of the perceptions of the participants (Smith, Jarman, & Osborn, 1999).

Therefore, an explication of the researcher’s own related experiences is central and this was incorporated in the initial pages of this dissertation under the heading ‘position of the researcher’.

A phenomenological inquiry can take varying forms but there are three common characteristics. Firstly in-depth accounts are collected from participants who have experienced the phenomenon of interest, secondly the meanings are identified which inform the basis of the third process of interpretation (Chamberlain, Comic, & Yardley, 2004). In the current project, this is focused on perceptions of need related to the therapeutic and support services available to

children with dual intellectual disability and emotional and/or behavioural difficulties. A phenomenological approach is particularly applicable given that the topic is a relatively new area of inquiry, however it has been applied previously in research within the health and disability field (Scior & Grierson, 2004; Smith, Jarman, & Osborn, 1999). Therefore, a comprehensive understanding of a smaller number of cases has the potential to generate hypotheses for future research, especially given that the current project is a pilot study of the methods for a potential doctoral level project. The procedure for analysis of the information gathered is described later in this chapter.

Quantitative Component

The quantitative methods proposed in the current study are psychometric measures developed for identification and assessment of the severity of a child's cognitive ability, adaptive behaviour functioning and emotional and/or behavioural difficulties. Their use in the present study will enable the type and severity of difficulties to be estimated and allow initial comparisons with the nature and scale of the educational, health and welfare services the child and family receive. To enable reliable and valid comparisons to be made on the basis of the type and severity of emotional and/or behavioural difficulties, it would be necessary to access a representative sample of the children in Christchurch who meet the inclusion criteria for the proposed study.

Importantly, the sample size would need to be large enough to include a statistically appropriate number of children in each range of severity of both intellectual disability and emotional and/or behavioural difficulties. Only in this situation could valid comparisons be made between the scale and nature of services and type and severity of emotional and/or behavioural difficulties. A sample which meets these criteria was unfortunately beyond the scale of this project. However, it

was deemed important to still have some means of estimating the difficulties for the children in the sample therefore the measures were employed in that capacity. Furthermore, it enabled assessment of the scales' potential for use in a future doctoral level study with a larger sample.

Qualitative Component

A semi-structured interview was employed to gather information about the nature and scale of services, and the extent to which they are meet perceived service needs. An extensive review of the literature highlighted that both qualitative and quantitative approaches had been applied previously to evaluate perceptions of service needs. However, qualitative methods were determined to have provided more detailed and applicable information in relation to how services are meeting needs of children with dual disabilities and their families. Semi-structured interviews are commonly utilised in qualitative research informed by a phenomenological perspective as they enable in-depth information to be obtained from participants, therefore facilitating a thorough evaluation of the research question.

Subjects

The subjects of the current study were children who have dual intellectual disability and emotional and/or behavioural difficulties. The sampling frame criteria was five to twelve year old children with previously identified intellectual disability and concurrent emotional and/or behavioural difficulties who are attending a mainstream primary school in the greater Christchurch city region. The sampling frame excluded children with an autistic spectrum disorder for two reasons. There is currently a lack of diagnostic clarity, in that the extent to

which a differential diagnosis on Axis' I and II of the DSM-IV-TR can be determined for intellectual disability and an autistic spectrum disorder is currently debateable. Furthermore, due to the pervasiveness of an autistic spectrum disorder, the therapeutic and support services for this group are probably more established than those for children with other DSM-IV-TR Axis II difficulties (C. Mohr, personal communication, November 30th, 2007). Given the small sample in the present study it was determined that a focus on the latter group of children was most appropriate. No other exclusion criteria were applied therefore other variables were accommodated in the present study. For example, index children could have identified with any ethnic background, and potentially experience physical disabilities as well as dual intellectual disability and emotional and/or behavioural difficulties.

Subject Sampling and Recruitment of Parent Respondents

Overall, a purposive sampling strategy was employed in the current study, in which personal contacts of the researcher were used to identify potential participant recruitment sources for both parent and service provider participants. Three of the parents who responded in the study were identified from the database of children receiving funding and support from a special educational support provider in the Christchurch city region. A simple random sample (Kemper, Stringfield, & Teddlie, 2003) was drawn from the pool of children who met the inclusion criteria and letters went sent to 40 potential respondent parents. Six 'Sampling Consent' forms (see Appendix B) were returned to the researcher of which three were determined to be ineligible due to their disabilities being primarily physical according to parent report. Initially respondents were recruited from this one database because it was deemed highly probable that all children in the target population would be receiving support from this service provider therefore ensuring a

representative sample of all children and parents who may be eligible for the current study. Because an insufficient number of respondents were obtained through this method within the time scale of the current study, four other service providers were subsequently approached and asked whether they would contact families who met the inclusion criteria. Another two parent respondents of children who met the inclusion criteria stated above were recruited through one of the approached service providers. From this point the parent respondents will be referred to as participants. Using purposive convenience sampling (Kemper, Stringfield, & Teddlie, 2003), four managers of service providers were approached to participate in the current study. The three managers that consented to participate are currently employed in different fields related to service provision for the target group, both governmental and non-governmental organisations. A demographic profile of all participants is provided in Table 1.

Table 1: *Research Participant Profile*

Participant status (F or SP)	Family no.	Gender of participant	Name of subject (age)	Gender of subject	Ethnicity	Severity intellectual disability	Length of career in years
F	One	Female	Charlie (12)	Male	European	Moderate	-
F	Two	Female	Helen (8)	Female	European	Moderate	-
F	Three	1 Male, 1 Female	Callum (7)	Male	European	Mild	-
F	Four	Female	James (8)	Male	European	Moderate	-
F	Five	Female	Catherine (6)	Female	European	Mild	-
SP	One	Female	-	-	European	-	9
SP	Two	Female	-	-	European	-	5
SP	Three	Male	-	-	European	-	9

Note: F = Family, SP = Service Provider.

Parents/Caregivers.

Once Human Ethics Committee approval was confirmed, approval from the Professional Practice research office and the manager of the special education service provider was sought and received. A staff member from this organisation, instructed by the manager of the service provider, randomly selected 20 children who satisfied the sampling frame criteria from the database and sent out a package to parents/caregivers. It included a letter from the provider to introduce the study, an Information Sheet (see Appendix B), a Sampling Consent Form (see Appendix B) and a stamped envelope addressed to the researcher. Potential participants were asked to complete and return the Sampling Consent Form if they consented to being a part of the sampling phase of the study. Four Sampling Consent Forms were received within a two week period. When this consent was received by the researcher, the potential participant was contacted by phone by the researcher and asked whether they verbally consented to take part in the data collection phase of the study. If verbal consent was obtained, the researcher confirmed that the child was likely to meet the inclusion criteria for the study and if so, subsequently organised a date, time and location convenient to the participant for the data collection to occur. Because less than ten potential participants sent back Sampling Consent Forms, a further 20 packages were sent out to potential participants. Another two Sampling Consent forms were received back and the same process for contacting the participants was followed.

Due to the small number of replies from the initial attempt at participant recruitment, four other service providers were approached by phone and asked about the possibility for participants to be recruited through them a similar method to that described above to ensure ethical requirements were maintained. One service provider agreed to do so within the timeframe

of the current study and a further two participants were recruited through this means. A senior member of the service provider identified and contacted the families to give them some information and ask whether they would consent to the researcher contacting them to explain the study and what their participation would involve. In instances where the families verbally consented, the service provider communicated the contact details back to the researcher. The researcher then phoned participants and if, after the study had been explained, they verbally consented to participate then the researcher organised a date, time and location convenient to the participant for data collection to occur. A total of five parent participants were recruited within the time scale of the present study. Recruitment of parent participants took place over a period of five months and a log of this process is included in Appendix H.

Service Providers.

Managerial staff members of three service providers were approached by either phone or email about their participation in the current study. All were known by the researcher to be appropriately involved in the provision of services to families such as those involved in the study. Two participants were contacted by email, which detailed the purpose of the study and what their participation would involve. A copy of the information sheet in Appendix C was attached to this email. Due to difficulty contacting one potential participant, the researcher phoned this person and provided information similar to that contained in the email. If the potential participant provisionally consented to be involved, a date, time and location at their convenience were arranged for a meeting to occur. A total of three managers' of service providers were recruited within the time scale of the present study.

Procedure

Data Collection: Tools.

The following section details the quantitative and qualitative tools that were utilised for data collection in the current research study. Each tool will be described, including both strengths and short comings, justifying their inclusion in a mixed method design utilising predominantly qualitative data gathering and analysis tools.

Adaptive Behaviour Assessment System – Second Edition (ABAS-II)

Harrison and Oakland (2003) designed and validated the ABAS-II for use as a measure of an individuals adaptive functioning in daily life from age five to eighty nine. It is a checklist measure in which the informant (self, parent/caregiver or teacher report) gives a likert scale rating of an individual's abilities on items divided into ten adaptive skill areas. These areas correspond with those included in the DSM-IV-TR criteria for diagnosis of mental retardation. The areas are; Communication, Community Use, Functional Academics, Home Living, Health and Safety, Leisure, Self-care, Self-direction, Social and Work (where appropriate). A General Adaptive Composite (GAC) score is derived from three sub-domains, Conceptual, Social and Practical, which comprise the skill areas. Scores are derived from each area and may be utilised identify areas for potential intervention and development (Harrison & Oakland, 2003). The ABAS-II is scientifically validated and is considered valid for use for both clinical and research purposes (Perkins-Dock, 2003). The norms have been derived from an American population which is not ideal in the current study given the cultural differences compared to a New Zealand

population. However, it was determined that there was no other comparable measure of adaptive functioning which has norms for a New Zealand population.

This quantitative measure was included in the current study because of its validated ability to estimate an individual's adaptive behaviour strengths and weaknesses. This is an important consideration when evaluating service provision, in particular to identify areas in which the child and family require intervention. There are a number of other similar measures available, such as the Vineland Adaptive Behaviour Scales (Sparrow, Cicchetti, & Balla, 2006) and Scales of Independent Behaviour – Revised (Bruininks, Woodcock, Weatherman, & Hill, 1984). After careful consideration, the ABAS-II was chosen because of its favourable test review (Perkins-Dock, 2003), robust psychometric properties, ease of administration and availability to the researcher.

The psychometric properties of the ABAS-II have been established by applying a number of measures of reliability and validity. The values described below are reported in the manual for the ABAS-II (Harrison & Oakland, 2003) and relate to the Parent Form for all ages due to the variability in age of the children in the current study. The ABAS and ABAS-II are highly reliable, indicated by internal consistency reliability coefficients higher than .80 for both sub-domain scores and the General Adaptive Composite (GAC). Test-retest reliability scores were estimated using Pearson's product-moment correlation coefficient. The reliability coefficient for the GAC is .88, and ranges between .84 and .86 for the three domains. Inter-rater reliability coefficients were derived with the same procedure indicating a GAC coefficient of .91 and domain coefficients of .84 (Conceptual), .76 (Social) and .91 (Practical). Studies of validity have evaluated the measure in relation to measures of cognitive functioning, particularly the Wechsler

Scales of Intelligence, and indicated that the measure is a useful tool for determining intellectual disability. Clinical studies have investigated sensitivity and specificity, finding that the ABAS is sensitive in distinguishing cases and non-cases and differentiates between levels of disability indicating good specificity.

Developmental Behaviour Checklist (DBC)

The DBC is a measure of emotional and behavioural difficulties specifically designed by Einfeld and Tonge (1995) for children with intellectual disability. It is a checklist of 96 items which reflect the emotional and behavioural difficulties commonly experienced in the target population. Five sub-scale scores and a total problem score are derived from the ratings on a zero to two likert scale. The sub-scales are Conduct Problems, Emotional Problems, Hyperactivity, Peer Problems and Prosocial Behaviour. Modelled on the structure of the widely used Child Behaviour Checklist (CBCL) from the Achenbach System of Empirically Based Assessment (ASEBA), the DBC is relevant for application as a quantitative measure in both clinical and research contexts (Einfeld & Tonge, 2002).

The DBC is utilised in the current study because of its ability to accurately identify areas of emotional and/or behavioural difficulty in the target population. As with the ABAS-II measure of adaptive functioning, identification of such difficulties is an important component of assessment for delivery of intervention services. Similarly it was chosen because of its reliable and valid psychometric properties, ease of administration and availability to the researcher. Furthermore, the measure has been normed with an Australian population which although not optimal, is probably closer matched to the New Zealand population than norms from other countries.

The Manual for the DBC (Einfeld & Tonge, 2002) reports the psychometric properties of the instrument. A summary is presented in Table 2, for which the values have been drawn from the Manual. A series of inter-rater reliability trials have been conducted with parents and nurses to progressively refine the items included in the checklist. A high level of agreement has emerged with an intra-class correlation (ICC) of .80 between parents and -.83 between nurses. Test-retest reliability has also been determined to be high for these groups. Content validity was established after interviewing 70 informants therefore indicating that informants were able to comprehend the items as intended and the included items reliably distinguished between behaviours which were the result of behavioural disturbance not secondary to developmental delay. Construct validity was established with a Chronbach's alpha value of .94. Concurrent validity and Criterion group validity measures were also good. The sensitivity and specificity of the measure was determined utilising a Receiver Operating Characteristics (ROC) with the area under the curve being estimated at 92%, indicating a good ability to distinguish cases from non-cases. The clinical cut-off score of 46 for the DBC-P was determined using this statistic.

Table 2: *Psychometric Properties for the Developmental Behaviour Checklist – Parent*

Study	No. of participants		
Inter-rater reliability			
Parent-parent	42	ICC=0.80	99CI=0.59-0.90
Internal consistency	110	=0.941	
Clinician-parent agreement	70	97%	
Criterion group validity	70	t=7.783	p<0.001
Concurrent validity			
DBC/ABS	40	0.86	p<0.001
DBC/SIB	40	0.70	p<0.001
Clinician ratings/DBC	70	r=0.81	p<0.001
Receiver operating			
Characteristics (ROC)		Area under ROC curve=92%	

Semi-structured Interview

A semi-structured interview is commonly used as a qualitative data collection tool because it facilitates the gathering of in-depth information from the participant whilst enabling the researcher to manage the course of the conversation (Creswell, 2003). A semi-structured interview can take various forms however in general it is based upon a series of questions which are asked of each respondent (Wilkinson, Joffe, & Yardley, 2004). This structure is subsequently utilised as a guide for analysis of the responses across individuals (Wilkinson, Joffe, & Yardley, 2004). As the qualitative component of the mixed method design adopted in the current study, the aim of the semi-structured interview with parents was to gather information about which services the child and family receive and parent perceptions regarding how those services are meeting their needs for therapeutic and support services. The interview structure utilised in the current study is included in Appendix D. It includes questions about the services the child has received in the educational, health (medical and psychological/psychiatric) and welfare sectors.

It then asks about areas that the parent feels the child is well-supported in, areas which are not well-supported with reasons and areas for improvement. This information is elicited for services overall and in each of the sectors. Lastly information about family support is sought with questions on what support has been provided, aspects that have been helpful, how they could have been better supported and support services for siblings of the dually disabled child.

A semi-structured interview format was also used with senior staff of service providers. The interview structure which was used with each service provider is included in Appendix E. The interview questions were designed to elicit the opinions of participants about how their service was meeting the needs of the target children and families and how the service structure as a whole is functioning to provide services.

Data Collection: Processes.

This section details the data collection processes undertaken in the current study.

Parent/Caregiver Data Collection

At a time and date arranged by phone, the researcher visited the parent(s) who had verbally agreed to participate in the study. Before beginning the data collection phase the researcher presented another copy of the Information Sheet that had been sent out previously in the survey package. After ensuring they understood what was involved in the study, outlining ethical and confidentiality considerations and answering any questions, written consent was obtained on the Parent/Caregiver Consent Form. Two points were particularly highlighted on the form, firstly the parents permission to have the interview audio recorded and secondly permission for the researcher to contact service providers to gain information only about the type and content of

therapeutic or support service if the researcher deemed it important for the findings of the current study. The information and consent forms used are included in Appendix B.

After spending some time establishing rapport the two quantitative questionnaires, the DBC and the ABAS-II, were introduced and completed. The researcher went through each questionnaire with the participants, providing instruction where necessary and clarifying questions. The researcher also asked the parent to indicate the severity of their child's intellectual disability according to the most recent cognitive assessment and asked to sight the results of this if it was available and the participant consented. All parents were able to give an indication of their child's severity of cognitive disability. Such assessment had occurred previously as a component of the assessment for either the intake and assessment process conducted by the special education provider for three of the participants. For the two participants not recruited through this method, they were able to give indication from assessment conducted during their involvement with other service providers.

Once the questionnaires were completed the semi-structured interview occurred. In one case, due to time constraints the instructions for completing the ABAS-II form were explained and it was left with the participants to complete at a convenient time so that the interview could be completed within the time available. The completed form was picked up by the researcher, who checked at this time that the form had been able to be filled out correctly. The researcher followed the structure of the Semi-structured Interview (see Appendix D) as closely as possible whilst also enabling the participant to have the opportunity to direct some of the conversation. Using previously learned interviewing skills the interviewer posed inquiring questions and interjected at appropriate points to ensure that the target topics were covered. Part of the aim of

the current study was to gain an overview of the therapeutic and support services that are being currently provided to children with dual intellectual disabilities and emotional and/or behavioural difficulties. This was not limited to just those directly associated with the intellectual or emotional and behavioural difficulties but also to those addressing physical needs and support for the family as a whole. This is justified because many organisations are now engaging in multidisciplinary team work as a current model of best practice (Rutherford-Turnbull-III, Stowe, Turnbull, & Schrandt, 2007). At the conclusion of the interview the researcher thanked the participant for their contribution and provided another opportunity for the participant to indicate whether or not they would like to review the transcript of the interview. No tangible reward was offered for participation in the current study.

Service Manager Data Collection

On the date and time arranged the researcher met with the participant. The purpose of the study and the details of what their participation would entail were explained again. The same information sheet that was previously attached to the email was presented. After ensuring that the information sheet had been read and understood, the consent form was completed. The researcher verbally checked with the staff member that they had the authority to consent to take part in this research. If this had not been the case, consent from the appropriate authority would have been sought in a manner adhering to the policies and procedures of the organisation. Before beginning the interview the participant was asked whether they would consent for the interview to be audio recorded and transcribed by an independent transcriber (see confidentiality agreement Appendix F). Their response was recorded in the appropriate space on the consent form. The semi-structured interview was then conducted using the topic questions outlined (see

Appendix E). At the conclusion of the interview the participant was thanked for their participation and given the opportunity to read the interview once it had been transcribed. If this was to occur the participant and researcher negotiated the arrangements for this to happen. No tangible reward was offered for their participation.

Data Analysis – Tools and Processes.

This section outlines the data analysis tools and processes utilised in the current study. The scoring and analysis of the two quantitative measures are outlined first before an explanation of the qualitative analysis process used to evaluate the transcripts of the semi-structured interviews.

Quantitative Tools

The two quantitative data collection tools utilised, the Adaptive Behaviour Assessment System (ABAS-II) and the Developmental Behaviour Checklist (DBC), both have data analysis instructions included in their corresponding manuals. The processes outlined in each manual were followed to analyse the data collected from each participant about the target child. A summary of this process is described next for each of the scales.

For the ABAS-II, the General Adaptive Composite (GAC) was considered as well as the three sub-domains and nine applicable skill areas. The individual item scores for each of the nine skill areas were added up and then converted from raw into scaled scores, potentially ranging from 1 to 19. The distribution of the scaled scores for each area has a mean of 10 and a standard deviation of 3. Therefore, if an index-child received scaled score of 7 or less, the corresponding skill area was considered as an adaptive functioning difficulty. Composite scores for each domain were determined by adding up the scaled scores of the appropriate skill areas. The total,

derived from the scaled scores, was located in the table of composite scores for the domain areas and GAC for the appropriate age range. The domain and GAC scores have a mean of 100 and a standard deviation of 15. Therefore, scores of 85 and 115 deviated by 1 standard deviation from the mean and scores of 70 and 130 deviate by standard deviations. Consistent with the DSM-IV-TR diagnostic criteria used in the present study, domain scores of 85 or under were considered to indicate a domain of adaptive functioning difficulty. The ABAS-II provides the following ranges which have been applied to describe scores in the present study; Extremely low (≤ 70), Borderline (71-79), Below Average (80-89), Average (90-110), Above Average (110-119), Superior (120-129), Very superior (≥ 130).

For the DBC, the Total Problem Behaviour Score (TBPS) and scores for each of the five subscales (Disruptive/Antisocial, Self-absorbed, Communication Disturbance, Anxiety and Social Relating) were considered. The score ranges for each of the sub-scales are 0-47+, 0-51+, 0-22+, 0-16+ and 0-16+ respectively and the score range for the TBPS is 0-126+. Both the scores and percentile ranking are reported in the findings. Each item was counted into the TBPS and its appropriate subscales (where applicable as not all items load onto a subscale). The totals for each were then transferred onto a separate score sheet and the percentiles derived. Percentiles range from 0-100, whereby, for example, a score on the 86th percentile indicates that the index-child had an equal or greater degree of difficulty than 86% of the norm sample, but 14% of the norm sample had an equal or greater degree of difficulty than the index-child. Percentiles may be determined according to the severity of intellectual disability, however this was not considered in the present study because the indication of cognitive difficulty was obtained from parent report, and therefore is not accurate enough for this purpose. The clinical cut-off for the TBPS on the

DBC is 46, which corresponds to a percentile of 58. The authors of the DBC indicate that scores above 46 indicate that the child's overall emotional and behavioural difficulties are clinically significant, however different clinical cut-off scores may be used depending upon the purposes of the research. For the purposes of the current research, the DBC will be used to identify the child's pattern of difficulties across the five sub-scales and the TBPS used to indicate the overall severity of the index-child's emotional and/or behavioural difficulties.

Qualitative Tools

The principles of Interpretive Phenomenological Analysis (IPA) (Smith, Jarman, & Osborn, 1999) guided analysis of the transcripts from both parent and service provider interviews. A number of potential qualitative analysis procedures were considered, however IPA was chosen because it reflects the theoretical foundations of the present project and its principles have been applied in previous peer reviewed research in the health and disability field. For example Scior and Grierson (2004) applied it to semi-structured interviews with service providers and Faust and Scior (2007) to examine semi-structured interviews with parents about the impact of children's disabilities on their lives. Furthermore, IPA permits in-depth description and interpretation of the lived experiences of a small number of participants in a relatively new area of inquiry (Smith, Jarman, & Osborn, 1999). IPA principles were appropriately adapted to facilitate analysis using Nvivo qualitative data analysis software (QSR International, 2006). The NVivo programme was employed because it enabled the researcher to handle the data more efficiently and flexibly (Richards, 2005). The analysis process is described in detail next.

Each audio recording was corresponded with the word processed transcript obtained from the transcriber to increase accuracy and re-familiarise the researcher with the tone of the

interview. Each transcript was then placed in one side of a two column table, with the transcript on the left and a blank column on the right to record descriptions and interpretations of the text in the form of initial themes. The researcher read through the transcript several times, noting down initial themes in the right hand column during each reading. The services provided to each family were also listed on a separate document, so that they could be identified and used to describe patterns of therapeutic and support services. The transcript was then imported into the NVivo software programme so that the text could be coded against the initial themes that had been identified. Where applicable, comments were also grouped according to the type of service that they referred to (e.g. education or psychological health). An example of this part of the coding procedure is included in Table 3.

Table 3: *Example of Transcript Coding Grid*

<p>*I So how have you found it, like accessing educational help? Like umm, I guess what's, what's your experience been of asking for help or knowing where to ask for help?</p> <p>*P Well, you don't know where to ask for help. You don't get a manual when your child's born as to umm, or when she goes into school as to what's available for you and there's umm, a lot of things and I think this comes more under welfare, through you know, you have a [need's assessment] agency or you have a umm, [special education] agency and the, you're only told certain things and it's, and you don't know, I mean I've never had a child before, let alone one with a disability and I don't know the questions to ask. I don't know what, what is actually available out there and that, it makes it quite hard and quite frustrating because it's not, I know other parents that we've been through [early intervention] with, we still keep in contact, and they're saying the same thing. We don't, we don't know and, and it's all, all the time, it's coming down to dollars and cents and that's what's really, really difficult.</p>	<p>Unsure of where to ask for help - confusion. No manual!</p> <p>Communication of information not consistent – things missed out. Lack of confidence due to inexperience. Frustration – common with other parents she knows. Parent-to-parent communication.</p> <p>Money: “all the time, it's coming down to dollars and cents and that's what's really, really difficult”.</p>
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Once coding had been completed, the themes within the transcripts were written on separate pieces of paper. The researcher then laid them out and drew connections between the themes in terms of how they related to aspects of service provision. For example, all themes related to ‘Service provider resources’ were grouped under that super-ordinate theme name. This structure was then transferred into the NVivo programme using ‘tree nodes’, which when selected opened up to show each of the individual themes and the coded text that corresponded. The text coded under each node was subsequently re-read to ensure that it was appropriately related to that theme. The names of the tree nodes were then reconsidered to ensure they reflected the content of the themes related to them. The final names of the tree nodes constitute the super-ordinate themes that provide the structure for reporting the results of this analysis in the Results section. It would have been preferable if the coding could have been cross-referenced with that of another researcher in the field of disability study. Unfortunately this was not possible due to time and resource constraints however it would certainly be a component of a follow-on study.

Ethical Implications

The University of Canterbury Human Ethics Committee provided ethics clearance for the present study. Following this approval, the national Professional Practice research office for the special education provider reviewed and approved the proposed method including all relevant forms (see Appendix A-E) before commencing the participant selection process at the regional level. For participants not recruited through this method, the appropriate policies and procedures of the service provider relating to participation in research for staff and consumers were followed.

Privacy and confidentiality were maintained to the greatest extent possible by adhering to processes demanded by both the Human Ethics Committee and service providers. All initial contacts to potential participants were made by the service providers without the researcher having knowledge of names and contact details. Once consent to contact potential participants had been received, the researcher did not communicate back to the service provider which parents had consented to taking part in either the sampling or data collection phase of research. All names of both participants and their families, and staff of service providers have been changed to pseudonyms and any other potentially identifying details removed from the report of findings.

While every effort was made not to induce distress, the nature of the subject being addressed in the current research is sensitive and may be a cause of significant stress in the family's daily life. In order to minimise the risk of distress the researcher endeavoured to conduct the parent interviews in an environment chosen by the participants and fully explained the information contained in the information and consent forms. If such distress occurred during the course of the interview the researcher utilised previously learned intervention skills and would have provided the opportunity for the participant to contact professional support had this been required. If participants identified with an ethnic origin that was not New Zealand European, the researcher sought advice from an appropriate cultural advisor from the University of Canterbury and from the participants themselves.

Participation in the current research project was entirely voluntary and participants were informed of their right to withdraw at any stage. Verbal consent was obtained during the initial phone call between the participant and researcher. Before commencing the interviews the

information sheet was fully explained to participants, they were asked whether or not they consented to an audio recording of the interview and whether or not they consented to the researcher contacting some or all of their service providers if applicable. The latter two points were explicitly stated on the consent form. The participants were informed that the audio recording, interview transcript, analysis of interview proceedings and written result were a component of assessment of a Master's dissertation. Due to time constraints the researcher contracted a person to transcribe the interview content from an oral to written format. This person was an experienced in transcribing research interview data and signed a confidentiality agreement prior to receiving audio recordings of the interviews (see Appendix F). This was explained to participants and verbal agreement was confirmed before transcribing occurred. Participants were asked whether they would like an opportunity to read and make changes to the transcribed interview and arrangements made for this to occur where relevant.

Chapter 4. Results

Introduction

The findings from the analyses of the corresponding data will be discussed in this chapter while further evaluation and interpretation will be presented in the discussion chapter. Case vignettes describing the family of each index child and the therapeutic and support services the child and family have received are presented first. All names used are pseudonyms. The type and severity of the index child's dual disabilities will be reported according to the results obtained from analysis of the Adaptive Behaviour Assessment System (Second Edition) (ABAS-II) and Developmental Behaviour Checklist (DBC). Following this is an in-depth description of the patterns of therapeutic and support services for the target group based on descriptive information detailed by both the parents and service providers who participated. Findings addressing perception of the therapeutic and support services provided to children with dual disabilities and their families, determined during the analysis of the semi-structured interviews, are then presented. The super-ordinate themes, derived using the principles of IPA, are explained and illustrated with examples from the interview transcripts. Themes from the parent interviews are presented first, followed by those from the interviews with service providers.

Case Vignettes

The results obtained for each index child on the ABAS-II and DBC are summarised in Tables 4 and 5. They will be further described in each of the following case vignettes. The scores for each

index child are discussed individually rather than collectively because of the small number. A collective discussion would not provide an accurate description of the type and severity of difficulties each child experiences. Table 6 indicates each of the types of services that the family reported that they receive. The intensity of each service provided is detailed in the corresponding case vignettes due to space restrictions in the table. Some of the therapeutic and support services have been specifically named because there is no possibility that the identities of the children, parents and families could be compromised. Where the researcher determined this was not the case, the purpose of the service is broadly described rather than the service being named.

Table 4: *ABAS-II Domain Area Composite Scores and General Adaptive Composite for each Index Child*

Child	Age	Domain Area Composite			General Adaptive Composite
		Conceptual	Social	Practical	
Charlie	12	59	78	40	54
Helen	8	50	61	40	42
Callum	7	61	75	83	68
James	8	50	64	46	46
Catherine	6	72	91	60	68

Note: Names of children are pseudonyms.

Table 5: *DBC Subscale and Total Behaviour Problem Scores for each Index Child*

Child	Age	Scale					TBPS
		Disruptive/ Antisocial	Self- Absorbed	Communication Disturbance	Anxiety	Social Relating	
Charlie	12	11 (50)	14 (58)	10 (88)	3 (48)	3 (48)	43 (54)
Helen	8	12 (54)	5 (22)	4 (46)	0 (0)	2 (36)	31 (38)
Callum	7	21 (78)	13 (56)	10 (88)	5 (72)	4 (58)	57 (74)
James	8	12 (54)	14 (58)	5 (56)	6 (80)	1 (20)	41 (50)
Catherine	6	16 (66)	12 (52)	5 (56)	5 (72)	2 (36)	41 (50)

Note: Percentiles are included in brackets beside the total score.

Table 6: *Types of Services Received by each Family*

Type of service	Family number				
	One	Two	Three	Four	Five
Education					
ORRS Funding	*	*	*	*	*
Teacher Aide	*	*	*	*	*
OT	*	*	*	*	*
Physiotherapy	*	*			
Speech-Language		*	*	*	*
Psychologist	*		*		
Transport Assistance		*			
Health					
General Practitioner	*	*	*	*	*
Paediatrician		*			*
OT	*	*	*	*	*
Physiotherapy	*	*	*		
Speech-Language		*	*	*	*
Psychologist	*		*		
Inpatient - Medical		*	*		
Outpatient - Medical	*	*	*	*	*
Family Welfare					
Disability Allowance		*	*	*	*
Carer Support		*	*	*	*
Home Support		*		*	
NGO					
Vision support	*				
Advocacy Support	*			*	*
Recreational		*			*
Holiday programme			*		
Informal Caring					
Grandparents	*	*	*		
Friends		*	*		

Note: * = service received. Blank space indicates service not received.

Family One: Charlie

Charlie, a 12 year old male, lives at home with his mother (Deborah), father and older brother. Charlie's mother completed both the ABAS-II and DBC forms. The scores obtained on the ABAS-II indicate that Charlie experiences difficulties in eight of the nine skills areas when compared to the norms for his same age peers, with leisure being the only skill area in which he is functioning at an age-appropriate level. Consistent with this, Charlie's highest composite score is in the Social domain where he functions in the borderline range. In the Conceptual and Practical domains Charlie is currently functioning in the Extremely Low range. The General Adaptive Composite Score is also in the Extremely Low range indicating that Charlie's overall adaptive functioning ability is better than 0.1% of children his own age. According to Charlie's scores, as rated by his mother, on the Developmental Behaviour Checklist his Total Problem Behaviour score is in the 54th percentile, which is not considered to represent a clinically significant level of behavioural and/or emotional difficulties for children with intellectual disabilities. The profile of subscale scores was relatively even, ranging from the 48th to the 58th percentile, with the Self-absorbed rating being the highest.

Charlie is in a mainstream class at his local intermediate school where he is supported by a teacher aide full time, mostly due to health and safety concerns. As described by this mother, Charlie has a moderate intellectual disability according to developmental cognitive assessment. He also experiences several physical disabilities including limited vision and slight spina bifida, which significantly affects his mobility. To enhance this Charlie has seen an occupational therapist approximately once per year and physiotherapist approximately monthly. Visual support services to teach him to use a cane are also provided. Charlie and his parents accessed

mental health services for assistance with behavioural difficulties including swearing and non-compliance. Possible psychologically based reasons for faecal incontinence were also investigated at this time, however this was determined to be more likely related to physical causes. While eligible for the Disability Allowance Charlie does not currently receive this. Informal supports identified by his mother included his grandmother and family friends.

Family Two: Helen

Helen, an 8 year old girl, lives at home with her mother (Elsie), father and younger sister. Helen's mother completed both the ABAS-II and DBC forms and indicated that Helen is considered to have moderate Global Developmental Delay. The scores allocated to Helen by her mother on the ABAS-II indicate that she experiences adaptive functioning difficulties in all nine areas measured. Areas of relative strength for Helen appear to lie in the Social domain, where she obtained scaled scores of two in the Leisure and Social skill areas compared to scores of one in the seven others. All of Helen's domain scores and the General Adaptive Composite lie in the Extremely Low range. This places her in the less than 0.1st percentile. While emotional and/or behavioural difficulties had been previously identified by the educational service provider the scores rated by her mother on the Developmental Behaviour Checklist do not indicate such difficulties. Her TBPS placed her on the 38th percentile, whilst the highest subscale score was Disruptive/Antisocial, the score for which corresponded to the 54th percentile. A higher score on this sub-scale is consistent with the behaviour difficulties that were later discussed during the semi-structured interview.

Helen attends a mainstream primary school close to her home, for which transport to and from is funded. She receives full time support from a teacher aide, part of which is funded by

educational services and rest by her parents using other funding avenues. As a component of the ORRS funding Helen receives occupational therapy once a term, physiotherapy one to two times per term and speech therapy fortnightly. She sees a private speech-language therapist weekly which is funded by her parents. Due to recent physical health difficulties Helen sees both a developmental and a neurological paediatrician. Her parents have not sought support for any behavioural or emotional difficulties because they felt they were not severe enough to warrant intervention. Helen receives the Child Disability Allowance. Carer support days have been allocated as well as five hours of home help per week. She has attended a recreational activity specifically for children with disabilities but she is now ineligible to do so again until a later date. Her mother identified her grandparents as significant informal supports, as well as friendships with other families who also have children with disabilities.

Family Three: Callum

Callum, a seven year old male, lives at home with his father (Paul), mother (Jo) and older sister. His parents indicated that James has a mild intellectual disability. The two measures of type and severity of disability were completed conjointly by his father and mother. The scores obtained on the ABAS-II indicate that, compared to children of the same age in the norm sample, Callum experiences adaptive functioning difficulties in all nine skill areas. There was, however, some scatter in the scaled scores for skills areas ranging from one, for Self-direction to seven, for Community Use, Home Living and Health and Safety. The composite scores for the three domains were 61, 75 and 83 for Conceptual, Social and Practical respectively. The GAC score indicates that Callum's adaptive functioning ability lies in the Extremely Low range however this result should be interpreted with caution given that there are significant differences due to

his strengths in the Practical domain. The scores assigned by his parents on the Developmental Behaviour Checklist indicate that he has a clinically significant Total Behaviour Problem Score which is in the 74th percentile. The profile of sub-scale scores is somewhat scattered with the most difficulties identified in the Disruptive/Antisocial Behaviour and Communication Disturbance scales respectively. The percentile range is 56 to 88.

Callum currently attends his local mainstream primary school with full time support from a teacher aide. This is partially funded through ORRS and topped up by the school. An occupational therapist, physiotherapist, speech-language therapist and psychologist have also been funded through ORRS however his parents were unsure of the frequency of these because it occurs during school hours. Paul and Jo indicated that their main source of support for his behaviour difficulties was strategies obtained during his IEP meetings at school. There have been no significant physical health difficulties apart from a recent operation to correct a visual difficulty, for which he has seen an optometrist. In terms of Family Welfare support, Callum receives the Disability Allowance and 12 days of carer support. The carer support days had recently been decreased from 18, the reason for which his parents were unsure of. To compensate they have an arrangement with a family friend who cares for his one weekend per month. His grandparents also provide some care however his parents expressed reservations about this due to age concerns. During the past two school holidays Callum has attended a one week holiday programme with other children from his community.

Family Four: James

James, a seven year old male, lives at home with his mother (Sally), father and two older brothers. Sally completed both the ABAS-II and the DBC. The scores obtained on the ABAS-II

indicated that James' adaptive functioning abilities are impaired in all nine skill areas, however there are two relative strengths in the areas of Leisure and Self-Care. This is consistent with the characteristics his mother reported during the semi-structured interview. The composite scores determined from the skill areas placed James in the Extremely low range in all three domains. Subsequently his GAC score also falls within this range, which corresponds to a percentile ranking of less than 0.1. According to the rating of his mother James does not have a clinically significant Total Behaviour Problem score however there is somewhat significant scatter in his sub-scale scores. In particular it appears that James could have difficulties managing Anxiety, with his score placing him in the 80th percentile. His scores on the other subscales range from the 20th to 58th percentiles.

James attends the local mainstream primary school where he is supported by a teacher aide for 15 hours per week, five of which are used during the lunch hour because of his high activity level. He also receives one hour per day of one-to-one instruction from a qualified teacher. This is funded through ORRS, as is a speech-language therapist that he sees every two to three weeks, and an occupational therapist approximately once a term. James's ears have not developed normally which affects this ability to hear, therefore he has appointments at a private clinic every three months to check his hearing and hearing aides. James is meant to have outpatient appointments in three hospital departments however these have not occurred in the past 18 months. If there are any immediate physical health concerns he sees his family doctor. With regard to Family Welfare, James receives the Child Disability Allowance and his family are entitled to 36 days of Carer Support per year and two hours home help per week. His mother said that they find it hard to use up the Carer Support days due to time and resource constraints.

James is actively involved in two local seasonal sport clubs. He and his mother belong to an association which supports children with his specific cause of intellectual disability. Through this they keep in contact with three other families which meet about twice per year for a social event and the mothers meet about monthly for a social catch up.

Family Five: Catherine

Catherine, a six year old female, lives at home with her mother (Melanie), father and two younger siblings. Her mother described the severity of her intellectual disability as mild according to the most recent cognitive assessment that she could remember. This is consistent with her ABAS-II scores as rated by her mother. Her scaled scores for the skill areas on the ABAS-II ranged between three and eight indicating that she has adaptive functioning difficulties in seven of the nine areas. Two areas of relative strength were Leisure and Social whilst her three lowest scaled scores were in Community Use, Health and Safety and Self-Direction. Catherine's domain scores are somewhat scattered, particularly indicating a strength in the Social Domain where she scored in the Average range. The area of greatest difficulty according to this administration of the ABAS-II appears to be in the Practical domain in which she is placed in the 0.4th percentile. Due to significant variation in the composite scores her GAC score is not interpretable. Her mother's ratings on this administration of the Developmental Behaviour Checklist indicate that her Total Behaviour Problem score is 41, which is not above the clinical cut-off. There was however somewhat significant scatter in her sub-scale scores, with percentiles ranging from 72 on the Anxiety subscale down to 36 on the Social Relating subscale. Her low score on the Social Relating subscale is consistent with her strength in the Social domain on the ABAS-II. This administration of the DBC also placed Catherine on the 66th percentile for

Disruptive/Antisocial Behaviour. This is consistent with the behaviour difficulties explained by her mother which have mostly occurred in the school setting.

Catherine attends an integrated school in a neighbouring suburb in which she is included in a mainstream classroom. She is currently funded for 12.5 hours of teacher aide time and an hour per day of one-to-one instruction with a qualified teacher. Her funded teacher aide hours have recently been decreased from 14 however with additional funding from the school and her parents the total number of hours will stay at 14. This has been cause of significant stress for her parents as they actually applied to increase the hours up to 17 because of some significant behavioural difficulties which had begun last year. They believe that if a psychologist had been involved, as they had asked, then the hours may not have been decreased. Catherine receives support from an occupational therapist once per term, a physiotherapist twice per term and speech language input three times per term. Due to communication difficulties her parents are considering accessing additional speech-language therapy privately. With regard to physical health, Catherine has few difficulties besides ongoing gluten and lactose intolerance. Her immediate health concerns are addressed by the family general practitioner when required and she attends two yearly paediatric appointments. Her mother organises to get Catherine's hearing tested privately each year due to difficulties getting appointments in the public system. Catherine receives the Child Disability Allowance and the family is entitled to 30 days of Carer Support. Catherine's grandparents also provide intermittent caring for Catherine. All three children participate in recreational activities together. The family also keeps in contact with other families they know through an association for children with similar disabilities, with whom they meet up about four times per year.

Patterns of Therapeutic and Support Services Provision

The purpose of the following section is to describe the pattern of therapeutic and support services provision for children with dual intellectual disability and emotional and/or behavioural difficulties in Christchurch, New Zealand. The description is informed by the semi-structured interviews conducted with both parents of index-children and managers of services who have a role in support services provision for the target group. Because of the small number of parent participants, the therapeutic and support services provided to them cannot be assumed to represent the experience of all children with dual disabilities, particularly given the difference in specific needs between children. Therefore, information from the three staff of service providers is incorporated to enable a more complete description to be drawn. This description will provide the background upon which understandings about the experience of service provision from the points of view of both parents and service providers can be interpreted in the next section.

During analysis of the semi-structured interviews with parents the therapeutic and support services provided to each family were identified and listed, firstly for each index child and secondly collectively for all children. The types of service provision for children in the target population in the present study were then grouped into five broad categories; Education, Health (physical and psychological), Family Welfare, Non-Governmental Organisations (NGO's) and Informal support. These five categories are not exclusive, in that some service providers may provide services that can be assigned to more than one category. For example, one NGO that provides foster care, shared care and home support can also be assigned to service provision in the Family Welfare category. Therefore, each service identified was assigned to the category it

was most closely associated. As in the case vignettes, services are not named where it was determined that doing so could potentially enable identification of the children, parents and families who participated.

Education

With regard to education, all index children in the present study received various educational supports within a mainstream school. The children were all included in mainstream classrooms with peers of their own age and all schools were located within reasonable range of their homes. The majority of educational supports were funded through the government's special education provider. Some additional educational services were provided at the discretion of parents, for example one parent was paying privately for weekly speech language therapy and another was considering it. According to the educational support provider interviewed, children can qualify for intervention for either communication or behavioural difficulties which impact on learning, or complex needs when there is a combination of the two. All index children in the present study qualified for the highest funding category, the Ongoing and Reviewable Resourcing Scheme (ORRS). Services which were provided with this funding included; specialist therapists, additional teaching from a qualified teacher, teacher aide support and material learning supports. All children received a combination of occupational therapy, physiotherapy and speech language therapy during school hours. Services from a psychologist were only provided where the child had been determined to have severe behavioural difficulties according to the criteria of the special education provider. Instruction from a qualified teacher for one hour per day was provided for all children however the number of hours during which they are supported by a teacher aide varied from 12.5 per week to full time. Some children had teacher aides funded

through other sources if it was determined by the parents and school that the allocated hours were not sufficient. As a component of the ORRS funding, two parents reported that there was a lump sum of money given to the school which was used to buy in extra learning supports for the child over and above those required for non-funded children.

Physical Health

The index children in the present study all received a variety of medical health services dependent upon their individual needs. All children were under the care of a general practitioner who managed routine health requirements. Parents reported that to receive the Child Disability Allowance, which will be further discussed under the Family Welfare category, the general practitioner is required to provide certification of the child's disabilities. Depending upon the financial means of their parents children received additional physical health care in either the public system administered by the Canterbury District Health Board (CDHB) or a mixture of public and private practitioners. As a component of Early Intervention services (before age 5) all children had been under the care of a paediatrician. The frequency of paediatrician visits was variable, seemingly dependent upon whether or not parent's contacted the service to make an appointment for their child. Specialist services were provided as required determined by the type and severity of the child's physical health difficulties. The frequency pattern for these services also varied with four parents also reporting that this was dependent upon whether or not they made contact with the service to organise an appointment. Specialist difficulties were most often related to vision and hearing difficulties. One child attended a hearing clinic which was not provided through the public health system. Parent report indicated that one child had required inpatient physical health services two times in the eighteen months prior to the interview.

Psychological Health

There are two major mental health related governmental providers of intervention services for children with dual disabilities in Christchurch, Child and Adolescent Mental Health Services (CAMHS) and Intellectually Disabled Persons Health. Both of these are located under the umbrella of the Canterbury District Health Board (CDHB) and are government funded by the Ministry of Health. The CAMHS service includes a Youth Inpatient Unit/Youth Day Programme, Youth Speciality Service, Child and Family Inpatient Unit/Day Programme, Child and Family Outpatient Service (Whakatata House), Family Mental Health Service, and a Refugee and Migrant Service. Of the five index children in the present study, one had attended such services with his parents for behavioural difficulties. The other branch of psychological service provision for children with dual disabilities is included under the umbrella of Intellectually Disabled Persons Health. This umbrella service includes an Assessment, Treatment and Rehabilitation Unit, Psychological Services for Adults with Intellectual Disability (PSAID) Inpatient Unit, Intellectual Disability Community Team, Consult Liaison Team, Dual Disabilities Houses and the PSAID Outpatient team. The main provider of services for children with dual disabilities under this umbrella group is the Intellectual Disability Community Team (IDCT). The IDCT provides clinical and educational services to children and their parents from the age of 5. The referral criteria for this service stipulate that only children with dual intellectual disability and challenging behaviour are eligible for this service, therefore emotional difficulties are the responsibility of CAMHS services. As discussed, each of these CDHB services has specific criteria which must be met for access to services however none are solely responsible for

provision of services to children between five and twelve who have dual intellectual disability and emotional and/or behavioural difficulties.

Family Welfare

Due to the increased costs of caring for a child with a dual intellectual disability and emotional and/or behavioural difficulties, there are financial and practical services available to supplement the care responsibilities of parents and caregivers. Two types of funding are available through the Ministry of Social Development, the Disability Allowance and the Child Disability Allowance. All children in the present study were eligible to receive the Child Disability Allowance. One child was not currently receiving the funding because his parents had not yet re-applied for the year. The allowance is intended for use to reimburse the ongoing and regular costs that children incur because of their disability (Ministry of Social Development, 2007). Carer support, otherwise termed respite care, is allocated to each family through a Needs Assessment Service Coordination (NASC) agency contracted by the Ministry of Health. The families in the current study were funded for between 12 and 36 days of respite care per year and two received home support, one for two hours and the other five.

Non-Governmental Organisations (NGO's)

A range of NGO's were reported to be involved in support services provision for children and families in the current study. Some provided recreational supports for the child and family whilst others were contracted by the government to provide specific support services. Recreational support services were based around one type of activity, for example sport or a club. Some families accessed just one whereas others accessed more depending on factors such as their

child's abilities, financial restrictions and logistical reasons such as transport and childcare for siblings. Another type of NGO services are those that specifically support people with disabilities, whether specifically related to the cause of their disability or more broadly. The purposes of such organisations were related to advocacy, provision of specific aides to enhance adaptive functioning and networking with other families with children with similar disabilities. Families had varying degrees of involvement with such organisations depending on the nature and severity of their child's dual difficulties and specific family factors such as time and financial means.

Informal Supports

All parents reported that they had supports which were not accessed through an external organisation. The most common of these was care provided by grandparents and other extended family members. Some parents also had friends who could provide care for the child. But perhaps the most frequent informal support was that provided within the immediate family by partners and siblings. All four of the mothers interviewed referred to the support provided by their partners as particularly important, particularly during times of stress when accessing formal services for their child.

Perceptions of Therapeutic and Support Services – Parents

Using the principles and adapted methods of IPA, the transcripts from the semi-structured interviews with parents were analysed. This analysis identified four super-ordinate themes which characterised the provision of services to children with dual disabilities and their families who

participated in the present study. Each of the super-ordinate themes has been named to reflect the cluster of themes contained within it. Rather than presenting a discussion of each of the themes separately under the respective super-ordinate theme, they are translated into a narrative account as is conventional in IPA (Smith, Jarman, & Osborn, 1999). The aim of the narrative account is to provide an interpretative explanation of the experience of accessing therapeutic and support services in Christchurch. Of particular importance is an accurate account presenting parents perceptions of how services are and are not meeting the needs of their child and family.

Direct quotes from the transcripts of the interviews are indented and single spaced. ‘*I’ represents the interviewer’s dialogue whilst ‘*P’ represents interviewee’s dialogue. The transcript source is identified using the family number (one to five) which is indicated in brackets at the conclusion of the quotation. Where the researcher has amended words to put the quotation in context this is contained in square brackets like this [*words*]. To protect identity and confidentiality the names of services have been changed and replaced with a description of the type of service. For example, where the actual name of a teacher aide was used, this has been replaced with the words ‘teacher aide’.

Theme One: Service Provider Resources.

Parents raised concerns about difficulties that they have experienced in accessing services due to a lack of and inconsistency of resources available from their service providers. Participants both directly and indirectly stated their perception that the financial resources of organisations were commonly associated with ability to provide effective levels of service provision. Two parents in particular communicated significant distress about the results of a lack funding that had impacted upon educational services provided for their child.

*P: If you don't have that support, it's alright getting the child into school but if you don't have that support carry on, what's the point of spending that money originally

*I: Yeah, yeah

*P: You may as well put all the children back in institutions, if that's what they're going to do. So it umm, and hence, so I'm writing a letter. It's not, it's not good enough. There's not enough money and there's not enough hours available to our children. (Family Five).

How resources are allocated and the subsequent impact on availability and continuity of service provider staff were, however, more commonly expressed as the result of parent's perception that there is a lack of funding. Ineffective distribution processes of resources, at both governmental and service provider levels, were identified as reasons why there are resourcing difficulties.

Parent's expressed anger about how priorities are determined for allocation of financial resources. At a governmental level one parent drew attention to the amounts of money spent on international sporting endeavours, when their child and others are struggling to receive an education which will prepare them with essential life skills for living as an adult in the community. All parents described situations where they had had to make desperate pleas for either extra resources or funding from a service provider for their child.

The ability of providers to supply services with a degree of continuity for the family was viewed as an important component of effective service provision, however the reality of this was somewhat mixed. The change in continuity of service provision during the transition from early intervention services to school services was identified by all parents. The intensity of support during years zero to five is much higher, therefore when children transitioned into school the decrease in consistency of support was significant for both the child and parents. Discussion about the transition process with all parents highlighted the considerable challenges faced as a result of the large number of changes in situation and specialist support. For example;

*P: So your early intervention teacher goes with you but basically, once you start school, you get a whole new speech therapist, a new physio, a new OT, everything is new

*I: Right

*P: And umm, when you're just doing a new school and everything else as well, it's difficult so Helen didn't actually start with a speech therapist at school because they didn't think she needed one. So she lost that service and then the teachers had to get her, that service back again. (Family 2).

Continuous involvement with the same staff from service providers appeared to enable parents to build a collaborative relationship for the benefit of their child. Furthermore, parents considered continuity to be important for the progress of their child. All index children had received consistent support from either one or two teacher aides and all parents made positive comments regarding this.

*P: He's been very lucky with the teacher aide hours that he has got and he's been very lucky with the teacher aides that he's received. Umm, [teacher aide one], who we had all the way through [a] School, so she was like a second Mum. She knew all of his good attributes and all of his bad ones. Umm, so and she knew how to deal with him. Over time, she was very, she knew, so that was always wonderful. Umm, [teacher aide 2] is the same.

Consistency of staff seemed to be less frequently experienced where specialist professionals are involved. Combined with the reality that the children only had input from such professionals infrequently, this was a concern for parents. The impacts of this were significant, in that they affected the child's ability to make progress in the respective area of expertise.

*P: the OT didn't know Helen very well when we first started school so that's one issue where we haven't been umm, supported particularly well. Umm, the fact that the OT didn't really want to be the lead case worker umm, and then you forever heard how big her caseload was and she would turn up at school without making an appointment and so if they were on a class trip, then Helen wouldn't be there

*I: And that was the end of it?

*P: And that was it. That was your, that was your assessment. (Family Two).

In summary, resourcing restrictions on the part of therapeutic and support services providers were perceived by parents to have a significant impact not only on the type and content of services they received, but also on the ability of their child to make progress. While there were several instances where parent's identified the positive results of adequate resourcing, when the interviews were examined collectively, examples of inadequate resourcing and its harmful implications, were very evident.

Theme Two: Variables Affecting Involvement

The super-ordinate theme 'variables affecting involvement' represents a collection of themes which have identified the reasons parents gave as to how and why they have accessed therapeutic and support services. The reasons identified are split into two broad groups, those that are related to the circumstances of the family and those which are more related to the current situation in Christchurch. The latter group will be discussed first as it provides a degree of context for understanding how family circumstances affect involvement with services.

Knowledge of services available was determined to be an essential component of the process of gaining access to services. The pathways to knowledge about services were frequently discussed. Parent's expressed concern that they were unaware of services that could potentially support their child because the processes for obtaining such information are so diverse.

*P: Well, you don't know where to ask for help. You don't get a manual when your child's born as to umm, or when she goes into school as to what's available for you and there's umm, a lot of things and I think this comes more under welfare, through you know, you have a [Needs Assessment] agency or you have a umm, [Special Education] agency and the, you're only told certain things and it's, and you don't know, I mean I've never had a child before, let alone one with a disability and I don't know the questions to ask. I don't know what, what is actually available out there and that, it makes it quite hard and quite frustrating because it's not, I know other parents that we've been through [the Early

Intervention Agency] with, we still keep in contact, and they're saying the same thing. (Family Five).

Comments such as the one above were made by all five parents. There is a desire for clearer pathways because if they were put in place, parents felt it would enable them to obtain a comprehensive knowledge of the services available. This would allay their fears that their child was missing out on a potentially effective therapeutic or support service because they had not known about it. Not receiving therapeutic and support services impacts negatively on not just the child with a disability but also the family as a whole. Examples of the negative impacts identified include financial implications, loss of time to meet the daily needs of other family members and increased levels of stress for parents. Most parents felt that other parents who have children with similar disabilities were their best source of information about what is available. The experience of caring for a child with dual disabilities was described as 'isolating', therefore the opportunity to network with other parents was highly valued. This was not only because they 'understood' what it was like to have a child with dual disabilities, but also because they could guide them as to where to access and what to expect from services.

Once parents have knowledge of a service that may be available to their child or family, the logistics of actually becoming involved are numerous. Parents found the experience of obtaining many services as laborious, disheartening and stressful. Because most services have strict referral criteria that require a certain degree of disability to be experienced before they will put in place services, some parents thought that the most productive way was to over-emphasise the child's difficulties during the initial process. Due to their feelings of desperation parents felt that they had to resort to 'telling little white lies' about the child's difficulties so that they could

attract the attention of staff of service providers. The focus 'on what the child can't do' is destructive to parent's hopes about what their child will be able to achieve.

*P: You spend five years of their life, initially, telling them, you know, you can do this, you can do this, you can do this. As soon as you get to school, ohh, she can't do this, she can't do this, she can't do this, to get money and it's so wrong. It's so very wrong, the way it goes. (Family Five).

Gaining access to a service often involves answering many questions and filling out forms which take a significant amount of time. Due to this, some parents prioritized the services and those which are not considered integral are not applied for. The experience of 'telling their story' to numerous service providers was described as frustrating and often pointless because the information was not communicated accurately to appropriate others.

The personal circumstances of the family also appear to determine the types of services that are available to them. Parent's related their perception of the level of severity of their child's emotional and behavioural difficulties to whether or not they sought help from mental health services. Of the five parents in the present study, one had accessed district health board mental health services, one had accessed a psychologist through their special education provider and one had asked for psychological input from their special education provider but not received it. The remaining two families reported a degree of emotional and/or behavioural difficulties but did not personally perceive that they were severe enough for them to access psychological services. All parents expressed a lack of understanding about some of the functions of their child's behaviour, for which some thought that specialist support would be useful.

*PM: We, we perhaps should be a bit more, you know, seek a little bit more in that area, perhaps because it would, it would be, it would definitely be a relief to just have somebody that we could call on, some, like the Super Nanny (Family Three).

Perhaps one of the biggest challenges to effective use of therapeutic and support services for the parents interviewed was on balancing the restrictions about what the service can and cannot provide with the needs of the child and family. Parents said that the restrictions and rules which determine how funding and resources can be used can actually make it hard to use services as they are intended. For example, they were frustrated that they had respite care days available but were unable to use them because they did not have anyone who could provide such care in a way that would meet the needs of their whole family, not just the child with dual disabilities. On the other hand, parents also recognised that restrictions do need to be placed around the use of support services to facilitate equity of service access.

*P: one of my hardest things has actually been finding, because I've been given 36 days, so that's three days a month and that's a lot

*I: Yeah

*P: In a month when he's at school five days a week and, you know, he plays sport and it's quite, at times, quite difficult to be able to use that umm, well currently, at our stage, anyway. It's not like we can say, right. The older two are off our hands and we'll go away for a week and James's cared for a week. Then you'd use a chunk, but we're not quite at that point. So I find that, we find that quite difficult

*I: Yeah

*P: To use to the maximum, to the intent it's meant (Family Four).

Due to difficulties obtaining enough funding and time from specialists, some parents had accessed private services at their own cost. In the cases of the five parents who participated, the two who had accessed private services were in a higher socio-economic status bracket. This was determined using one of the demographic questions on the ABAS-II which asks about the parent's occupation. While the two parents who had accessed private services for their child acknowledged the advantages of accessing private specialist services, they also raised associated

challenges including the making the time to go to appointments and the involvement of even greater numbers of staff in their child's care.

Theme Three: Working Together with Professionals

All parents discussed both positive and challenging experiences of working with the numerous professionals involved in support services provision for their child and family. The analysis indicated that while parents acknowledged the necessity for input from professionals, the practicality of working together was affected by a number of variables. The most commonly identified variable centred on communication between parents and professionals. All parents brought up examples of both rewarding and disappointing instances of communication between themselves and professionals. Parents valued relationships with professionals where they could freely articulate what they needed and trust that their concerns would be addressed. Furthermore, opportunities to talk with staff about how their child was progressing were considered as important. However tensions due to breakdowns in communication between both parents and service providers were evident in all interviews, particularly on the topic of finding out about services which they could potentially access.

*P: Isn't that [Need's assessment agency]'s job to let us know what we're entitled to and what we can, you know.

*I: Mmm

*P: So there's a lot of things like that that you don't, that you're not told about and, and if we didn't, if we weren't still with our group, you'd, you wouldn't hear about it (Family Five).

Many parents felt that often service providers did not take the circumstances of the family into account appropriately in their decisions about what services to provide and how to provide them. Often the focus is singularly on the child with dual disabilities. This raised challenges for parents

in terms of accessing any degree of support for themselves as fulltime caregivers and for siblings.

The attitude of staff of service providers towards the child and parents is perhaps one of the most significant predictors of a working relationship that benefits the child. For example, the ethos and attitude of schools towards accommodating a child with dual disabilities was an important factor in parent's decisions about where to enrol their child at primary school. Parent's felt encouraged when principals told them that their child's inclusion in the school was 'not a problem', and indicated that this built a sense of trust between them and the school that they would work together to meet the child's needs. On the other hand, all parents described experiences where the attitudes of staff of other service providers had caused stress. When parents had finally been able to access the specialist, to hear about how busy they are and that they had only taken on this case because there was no one else was discouraging. Parent's commented that such staff often assumed an expert stance when this occurred, making parents feel that their intimate knowledge of their child was not being appropriately considered.

*P: I find it difficult too, because a lot of professionals get quite arrogant and get quite caught up in they know everything and yet, quite frankly the parents know the child best and they really do need to listen. (Family Four).

Parents consistently described instances where the knowledge and expertise of professionals had benefitted their child. Where professionals had been able to address some of their worries about their child's future and current ability by intervening to enable the child to make progress, parents were particularly appreciative. An outstanding characteristic of these instances was a collaborative relationship between parents and service providers. Overall,

parents appreciated times when service providers were able to give assistance in such a way that not only benefitted the child but also acknowledged the integral role of parents.

Theme Four: Parent's Conceptualisation of Own and Others Roles in Service Provision

In relation to whether or not services are meeting needs as perceived by parents, participants talked at length about their role as a parent and also as an advocate for their child. Juggling the different components of their roles was a source of stress for parents. All parents made comments about the role which were similar to the following from the mother of family five; "I've described it as a weight on your shoulders all the time. Some days, it's very heavy, other times, it's just there". Parents indicated that they rely on support services to shoulder some of that weight at times. The burden of care inevitably increased for parents when services were not available, or when were forced to 'fight tooth and nail' to access them.

Differing levels of self-confidence in one's ability to advocate effectively for their child were expressed by parents. Self-confidence was not only related to how they approached services, but also a determinant of the extent to which they were facilitated to access them. For those who perceived themselves to have relatively high degrees of confidence in their ability to advocate for more services, persistence was identified as a key attribute. More than one parent used the term 'squeaky wheel' to describe how they have continually approached the same services over and over again and with increasing intensity.

*P: I think we are supported and we're hugely grateful for everything that we've got but you have to be a squeaky wheel and you have to ask for everything.
(Family Two).

*P: Umm, and the squeaky wheel often gets fixed. So I find that if, in the past, a quite polite phone call will generate an appointment and, and you know, you get seen. (Family Four).

Some parent's identified instances where they had expressed anger towards a service provider because their child had not received a service the parent believed they were entitled to. Both positive and negative consequences, in terms of increased service provision, had occurred as a result. However, without exception, parents indicated that a collaborative partnership in which each party fulfilled their appropriate roles was preferable. In summary, parents of children with dual disabilities felt that they not only had a role as parents but also as an advocate for their child's rights to provision of services. The role of advocate has the potential to be rewarding when services are put in place, however it was more often viewed as an additional burden.

Perception of Therapeutic and Support Services – Managers

Similarly to the parent transcripts, the principles and methods of IPA were used to analyse the semi-structured interviews with three managers of service providers. The analysis identified a number of common themes across the transcripts which have been drawn together into four super-ordinate themes. The discussion of each of the super-ordinate themes follows the same structure and conventions as described for parents above.

Theme One: Multi-agency Collaboration

Multi-agency collaboration was identified by all service providers as an essential component of service provision for children with dual disabilities, particularly because of the potential need for them to be involved with larger numbers of services. While interagency involvement is currently occurring in Christchurch, managers identified a number of difficulties that they themselves, and

the services as a whole, have encountered in meeting the needs of families by working together. Common perceptions that the services are separate entities, each with a specific scope of practice in one field, were identified as harmful. Funding restrictions and requirements that define the population of consumers that the service may work with were cited as one significant reason for the occurrence of such perceptions. The result of such attitudes was thought to enable services to pass on responsibility, meaning that service provision becomes inconsistent and fragmented for the family. To lessen this occurrence, participants identified increased knowledge about the purposes of other service providers as one area of need.

*P: I actually think that the organisations that are dealing with them need to actually start interacting. We don't. We don't know enough about each other and until we actually build a relationship with each other, we're going to continue to have that, no, they're out of your funding because they've got an intellectual disability rather than, we're going to work together or, no, you need to take that because it's a mental health. (Service Manager Two).

Furthermore, appreciation of the expertise of others was identified as a requirement to effectively together. By sharing knowledge between all staff involved in service provision for a child, it was thought that assessment and intervention could be more effective. For example, where agencies only work with a child and family infrequently, communication with those who work with the child consistently was thought to enhance the experience and outcomes for all involved.

Separate agencies have forged a number of links with other agencies and all managers expressed a desire for the links to grow in number and consistency. However, the qualification given to this by all participants was that this requires direction from a higher level than individual services. In other words, they felt that government ministries and high level managers should take action and provide guidance for the agencies to work together. A top-down approach was advocated as it was thought that this could induce the most significant positive change to

multi-agency collaboration. Increased multi-agency collaboration driven by higher level policies was described as a current area that requires attention. It was thought that this would enable the needs of children with dual disabilities and their families to more adequately addressed.

Service providers described instances where they had effected positive change in the lives of their consumers but, when their involvement ceased and consumers were referred on to other agencies, the improvements were not sustained because there was no-one to take responsibility. This was a particular concern for therapeutic/clinical services, which can only have limited involvement and rely on support services to provide ongoing care and support to the family.

*P: Our major frustration as clinicians is that we do a lot of good work and inevitably it falls over six months down the line because there's very little out there to continue the support that is needed and we need to get on with the next caseload and these guys, [support agency] and that, are equally frustrated because they also are only small organisations. (Service Manager Three).

Furthermore, managers cited a lack of clarity around decisions about who co-ordinates cases, particularly at transition points, with the result of children and families 'falling through the gaps'. A particularly pertinent example is the lack of a clear pathway into child mental health and intellectual disability services from early intervention services. One participant reported that there is currently no formal structure for this handover, partially because the different roles of intellectual disability and mental health services are not understood by those outside of those services.

Theme Two: Higher-level Influences on Service Provision

Without exception, managers identified how higher-level policies and procedures affect the capacity of services to provide for the needs of children with dual disabilities and their families. Predictably, the model of practice that an organisation adheres to differs significantly depending

upon the type of therapeutic and support services that the agency provides. Managers commented on the discrepancies of fit between the models of care between different services. One manager discussed at length at the lack of fit in models of care for intellectual disability and mental health.

*P: Historically and currently, the problem is that the way in which both services are configured has been different right from the outset. Mental health services are geared up, primarily to do an assessment, treatment and discharge. Our clients live with lifelong diagnoses and therefore we have a different approach style in terms of how we assess the length of involvement, who we will pull in and even what we might focus on at any given time. (Service Manager 3).

Because of this, the pathways to care for children with dual disability are inconsistent resulting in fragmentation between services. Another manager described a case where each service had diverging ideas about the next step for intervention, and expressed trepidation about how the conflict would be resolved for the best needs of the consumer. The lack of a clear model of care for disability at a national level was also highlighted as a reason for the discontinuity of care experienced by children with dual disabilities.

*P: We do not have a clear national coherent model of care

*I: Yeah

*P: For intellectual disability. It's hit and miss

*I: Yeah

*P: It's really hit and miss, as to whether a child gets picked up and referred through and lots of GPs then say, ohh, I didn't even know you guys existed

*I: Mmm

*P: You know, it's, and even clinicians within the [health agency], and a lot of them assume that we, the community team, will do the support and we say, no, we're actually clinicians. (Service Manager 3).

The strengths and challenges of the policies and procedures which guide how organisations provide services that meet the needs of children with dual disabilities and their families were discussed by all three managers. All identified the need for clear guidelines which dictate the type and content of services that are provided for reasons of equity and consistency.

The word accountability was also raised frequently, associated not just with accountability to parents but also to other service providers, the relevant ministry and the taxpayer. One organisation used the example of a recent change of focus to include measures of accountability, meaning that staff members are now required to demonstrate the effect of their intervention in quantifiable terms. However, challenges presented by referral criteria and scope of practice guidelines were also identified. Particularly in relation to their impact on the number of children with moderate dual disabilities who do not receive services because their difficulties are not classified as severe enough to warrant intervention from a certain service provider. It was universally acknowledged that there are a large group of children in Christchurch whose needs associated with dual disability are not being adequately met at present.

Theme Three: Resources

Financial, material and human resources were identified as central determinants of whether or not a service provider was meeting the needs of children with dual disabilities and their families. Difficulties in obtaining and distributing all three constituted a significant current challenge for all the managers. While specialists such as physiotherapists, occupational therapists and speech language therapists are in short supply, it was acknowledged that they are at least part of the multidisciplinary group providing services to children with dual disabilities. However, concern was raised not only about the lack of clarity about the pathways to service provision for emotional and behavioural difficulties, but also that there are actually no services available that accept total responsibility for meeting the mental health needs of children with dual disabilities. Furthermore, the services that are available to meet mental health needs are primarily based on

resolving challenging behaviour. Therefore the therapeutic/clinical services provided for children with emotional difficulties were acknowledged to be relatively inexistent.

*P: Well, there are hundreds of thousands of dollars that get poured into education. Yeah, the trick is, is it being spent well? Can we, can I say to you with my hand on my heart, that money is being used as well as it might be and so at the manager level, can I confidently say to you that my people, my team are doing the very best job that they can around a student? So it's, it's always tempting to say there's not enough money, there's not enough money, there's not enough money. There'll never be enough money so we jolly well better make sure that we're using the money as well as we can for the students. I still feel pretty passionate about it, in case you can't tell. (Service Manager One).

As the above quotation demonstrates, because the financial resources available to an organisation are necessarily finite, managers saw a major part of their role as ensuring that they were spent efficaciously. Once again, the distribution of resources was related to multi-agency collaboration and the irregularities present in how needs are assessed. Needs assessment methods are not perceived to be consistent and coherent, therefore managers indicated that staff are required to complete a lot of assessment tasks that have already been done previously by another organisation but are unusable to them in their current form. The impact of this on families, in terms of 'telling their story' multiple times and the frustration of having to wait for assessment before intervention can begin, was acknowledged.

Both a lack of staff and a lack of expertise in dual disability were identified as concerns for managers. Managers indicated that the type of service provided is to an extent determined by the expertise of the practitioner in the area of dual intellectual disability and emotional and/or behavioural difficulties. One manager identified the area as one that not many clinicians actually want to work in. The reasons given were both historical, the perception that all needs of people with intellectual disabilities should be provided from

with intellectual disability rather than mainstream services, and current, that there is a dearth of training in this area in mental health related disciplines.

*P: I mean there are good clinicians in there, but their remit is mental health and not intellectual disability. (Service Manager 3).

All managers brought up the subject of professional development for staff as an essential component of efficacious service provision. Support for staff through structured supervision and the opportunity to up-skill were noted as means through which professional development is occurring. An increase in resources to enable managers to facilitate this was identified as an ongoing need.

Theme Four: Collaboration with Families

All participants discussed how the nature of the relationship between the service provider and the family has a significant impact on whether or not the service is able to meet the needs of the family. The degree of collaboration with the family differed slightly between service providers due to their scopes of practice and models of care. One manager described how their service primarily works with the professionals who are working most closely and frequently with the child. While the family could potentially play an important part in this, because the service is mostly focused on one area, the integration of the family was somewhat limited. All managers described some of the challenges they had encountered while collaborating with families, particularly around parent perceptions of the degree to which they need to be involved in interventions for their child. They identified that communicating a professional opinion to families whilst accommodating their points of view about their needs was often challenging.

*P: For many of them, consistently, they've said they didn't realise the demands, that a behavioural plan would take so much and that's due to the sort of umm,

popular media image of what it takes. What people don't understand is that behaviours, and to change behavioural repertoires requires a minimum of three months of doing the same thing every single day[...]They've never anticipated that they would be part of the solution. They often think that somehow, the child will come in and we, as clinicians, will do something magical, like in Rain Man. (Service Manager Three).

All participants appeared to be sensitive to family circumstances and how they may affect their ability to integrate with services. They acknowledged that all families experience different challenges and therefore require approaches that are sensitive to that. When asked how they thought their service met the needs of children and families, the responses included both positive and negative elements. Service providers were also asked for their thoughts what parents would say about how their service meets their needs. In the process of answering this question all participants were careful to determine that parent's evaluations of a service were all likely to be vastly different, depending upon the service provided to them overall and its different components. While quality of the service was likely to be important, service providers thought that parent's complaints were more likely to be around quantity and frequency of service. The lack of clarity around roles of particular services and professionals was also raised an area where parents are likely to have misunderstandings and therefore unmet needs. The complexity of the needs that children with dual disabilities present with is increasing according to the participants in the current study, and this presents a significant challenge to providers in terms of balancing the need for difficulties to be addressed holistically but within the constraints of what the service can provide.

Chapter 5. Discussion

Introduction

A greater level and intensity of therapeutic and support services may be required for children with dual intellectual disabilities and emotional and/or behavioural difficulties because of the increased complexity of their care requirements (Einfeld & Tonge, 1996a; Einfeld & Tonge, 1996b). However, the extent to which needs are met is dependent upon the quality and quantity of therapeutic and support services available in the community (Carpenter, 2000). The purpose of the present study was to evaluate the current state of service provision for a target group of children with dual disabilities who attend mainstream schools in Christchurch, New Zealand. In order to provide an understanding of service provision for this target group, the perspectives of both parents and service providers were sought using in-depth semi-structured interviews. The interviews informed a description of the patterns of therapeutic and support services in the previous chapter. An Interpretative Phenomenological Analysis of the transcripts identified a series of super-ordinate themes that represent the experience of service provision for the participants in this study. It is now pertinent to consider these findings with reference to previous literature and evaluate the extent of convergence of parent and service manager perspectives.

This chapter will begin with a discussion of the super-ordinate themes identified from the interviews with both parents and service managers. Evaluation of the extent of convergence between the perspectives of the two groups of participants is incorporated throughout. The initial discussion specifically focuses on determinants of involvement with specialist services associated with dual disability and then broadens to include wider services. An additional aim of the current study was to evaluate the methods applied for their potential application in a future

doctoral level study. This evaluation is included before a discussion of the limitations pertaining to the present study. While the aim of the theory and methods applied in this study was not to produce an outcome that could be generalised to the entire target population (Brantlinger, Jimenez, Klingner, Pugach, & Richardson, 2005; Reid, Flowers, & Larkin, 2005), several recommendations which could improve the current state of therapeutic and support services will be presented at the conclusion of this chapter. Research hypotheses are proposed as the basis of a potential future study.

Perspectives on Service Provision – Parents and Service Managers

Themes

A principal aim of the present study was to extend current understanding about the lived experience of accessing therapeutic and support services for children with dual intellectual disability and emotional and/or behavioural difficulties. The following four super-ordinate themes were identified from the interviews with parents; service provider resources, variables affecting involvement, working together with professionals and parents conceptualisation of their own and others roles in service provision. Analysis of the interviews with service managers also resulted in four super-ordinate themes; multiagency collaboration, higher-level influences on service provision, resources and collaboration with families. Somewhat unexpectedly, the majority of identified themes were common to both groups of participants. Those that were not were mostly related to circumstances specific to the participant's roles. For example, service managers demonstrated an in-depth understanding of the constraints that determine who receives services, whereas parents focused on the impact on their child and family of not receiving a

service. Overall, the super-ordinate themes that were identified during analysis of the interviews with five parent and three service manager participants are collectively consistent with the types of scenarios experienced by similar populations in the research literature. This convergence will be demonstrated in the course of the following discussion.

Involvement with Specialist Intellectual Disability and Psychological Services

While the aim of the current study was to support an understanding of the broad patterns of therapeutic and support services provision for the target group, the focus on dual disability warrants separate consideration of the determinants of involvement with intellectual disability and psychological health services. Of the five index children whose parents participated in this study, two had received input from a mental health professional and one had approached a service for psychological support for their child but had not received it. The number of children with dual disabilities who receive intervention from mental health services tends to be disproportionate according to studies which have measured levels of provision (McCarthy & Boyd, 2002; Zwaanstijk, Verhaak, Bensing, Ende van der, & Verhulst, 2003). It is worth considering the reasons for a discrepancy between the number of children who have dual emotional and/or behavioural difficulties, and the number who receive the input of mental health services. The reasons stated by parents in the present study pertaining as to why they had not accessed mental health professionals for their child were varied. The following four reasons are consistent with those identified previously in the literature (Douma, Dekker, & Koot, 2006; Zwaanstijk, Verhaak, Bensing, Ende van der, & Verhulst, 2003); lack of knowledge of the type of service available, the perception that the child's difficulties would not be severe enough to receive services, parental self-confidence to access services and parental desire to address the

emotional and/or behavioural difficulty independently. Other reasons identified that are applicable to this sample include demographic factors such as socioeconomic status, informal social support and family composition (Douma, Dekker, & Koot, 2006).

The population of children with dual disabilities is not homogenous. The sampling frame for the present study was purposely devised to include those children and families whose pathways for accessing therapeutic and support services are probably the least well defined according to the research cited in the literature review. Therefore only children attending mainstream schools were selected for inclusion, because children in segregated schools are likely to have clearer pathways to services because of the supports more commonly available in a special school environment. For example, teachers in segregated special schools have a higher level of training to work with children with intellectual disabilities, and are therefore potentially more sensitive to identifying emotional and/or behavioural difficulties and initiating the involvement of therapeutic and support services (York-Barr, Sommerness, Duke, & Ghere, 2005). Evaluation of the differences in the extent of involvement with psychological services between mainstream and segregated children is not possible using the findings of the present study. However, the findings do indicate that a number of variables determine provision of specialist services for the target group of participants. Further identification of these variables is an area for future research, as it will enable dual disability providers to more accurately match the nature and scale of services to the needs of target children with dual disabilities and their families. Einfeld and Tonge (1996b) also highlighted the importance of targeting those with dual disabilities who have the greatest need for therapeutic and support services.

Pathways to Service Provision

The findings of the present study suggest that patterns of service provision in Christchurch are fragmented for the target group of children with dual disabilities and their families. Parent participants were concerned about a lack of clarity regarding the pathways through which they could find out about and access services. Informants about potential services were varied, with most parents identifying other parents who have children with similar disabilities as their main source of information. This finding is consistent with comparable studies that have indicated that the sharing of information about available services is one of the important functions of peer support from other parents (Crawford & Simonoff, 2003; Faust & Scior, 2007). Other informants about services included current service providers and needs assessment agencies but they were perceived by parents to be less reliable. As a result of the lack of clarity of pathways to services, parents in the present study were concerned that their child and family would not receive the services they were entitled to. Such concerns are justified given previous research findings which have found that there are a significant proportion of children with dual disabilities receiving inadequate services because referral pathways to providers are not explicit (Scior & Grierson, 2004).

The findings from interviews with the service managers also suggest a lack of clarity of pathways to provision of services for the target population. Incomplete knowledge of the purposes of other therapeutic and support services on the part of service staff was identified as one reason for referral of children and families to inappropriate services. This is a common feature of dual disability services according to previous research. For example, Scior and Grierson (2004) interviewed senior service providers about their perceptions of the extent to

which the mental health agency they were employed by was meeting the needs of children with disabilities. The authors concluded that both local and national initiatives to increase sharing of information about service functions between agencies were required. Inherent in the findings from both participant groups in the current study was the perception that there are significant dysfunctions associated with the systems and networks employed for communicating information about the services and support available to the target group. The implication of this directly relates to equity of service provision, whereby children and families could be better supported if systems were well defined and consistent. Moss, Bouras and Holt state that “pathways of care must be clear, accessible, appropriate and efficient” (2000, p. 102). According to the findings of the present study, a lack of consistent pathways to care characterises service provision in Christchurch. This indicates a current need for both governmental and non-governmental service providers to work together to improve consistency of services. The implementation of services which have clear access pathways has had positive implications for equity of service provision with comparable populations in the United Kingdom (Hall, Higgins, Parkes, Hssiotis, & Samuels, 2006).

Resourcing for Services

Parents and service managers both identified the current state of resources as a significant determinant of the level and intensity of services that could be provided. The majority of comments about resources were centred on their lack of availability to the child and family. A lack of resources within organisations that provide support services to children with dual disabilities is consistently cited in the research literature (Faust & Scior, 2007; Molony, 1993; Scior & Grierson, 2004). Inequitable distribution of resources was a common concern for parents

in the present study. Furthermore, infrequency and inconsistency of services had an impact on the degree of success parents felt their child could achieve in the respective area. Predictably, service managers raised issues regarding cost-effective allocation of financial resources and accountability. A dearth of professionals who have appropriate training and expertise to work in the area of dual disability was also identified by service managers. This is a widely acknowledged issue in the literature. A review of Australian and New Zealand services by Molony (1993) concluded that this is the result of a lack of professional interest in the area, unattractive remuneration and a lack of training opportunities. Overall, the findings of the present study are consistent with previous research, which has concluded that financial and staff resources are inadequate for the provision of services to children with dual disabilities. Revision of the processes for allocating resources to this group would be an essential component of a broader review of services.

Continuity of service provision, especially during the transition from early intervention to school services, was a related concern for parents. The availability of early intervention services is currently well supported by the research literature. Effective early intervention support has been associated with lesser degrees of mental health problems later in life (Guralnick, 2005). There is also justification for intensive and consistent early intervention services in other fields associated with service provision for children with dual diagnosis, such as occupational therapy and physiotherapy (Landesman Ramey, Ramey, & Gaines Lanzi, 2007). Involvement in early intervention was predominantly described as a positive experience by parents in the present study. However the decrease in the level and intensity of support services provision that occurred as children entered mainstream schools was identified as both disappointing and stressful. The

reduction in level of support was also recognised by two of the service managers employed in organisations associated with the transition from early intervention to school services. The findings of the present study suggest that the transition from early intervention to school focused services requires widespread attention so that the process is less stressful for the child and parents. Keller and Sterling-Honig (2004) made a similar recommendation in a study which examined stress factors in a comparable sample of mothers and fathers of school aged children with disabilities.

Multidisciplinary Services

The parents and service providers who participated in the present study described a multidisciplinary and multiagency network of therapeutic and support services for children with dual disabilities in Christchurch. Multidisciplinary practice, in which a number of professionals of different specialties are involved in one case, has become an increasingly common component of overall service provision both in New Zealand and internationally (Sloper, 2004).

Multidisciplinary team work can occur both within one organisation or span multiple service providers. The multidisciplinary team thus becomes a multi-agency network. Such an approach to practice is widely supported in the literature because it has been found to facilitate better outcomes, but only when implemented appropriately (King & Meyer, 2006; Morton et al., 2003). Unfortunately, a number of challenges currently facing effective multidisciplinary service provision for children with dual difficulties in Christchurch were identified by participants in the present study. Perhaps one of the most significant barriers identified was the lack of consistent links between agencies. Service managers highlighted that the reason for this is that the links are primarily established at an individual organisational level. Facilitation to build more consistent

links from higher level government ministries was a solution suggested which could provide a means for a more effective multidisciplinary and multi-agency service provision model. Previous research has concluded that the development of coherent policies will be essential to achieve significant improvements in service provision (Moss, Bouras, & Holt, 2000). Higher-level policy directives were identified as a key component of removing barriers to multidisciplinary work in an international review by Soper (2004). There is some evidence to suggest that closer links between agencies facilitates positive experiences of service provision for dual disability. For example, Mohr, Phillips, Curran and Rymill (2002) evaluated a training programme conducted with staff from both intellectual disability and mental health services. The programme aimed to educate staff about working with people with dual disabilities and encourage the two separate service streams to collaborate more effectively. The results indicated that staff confidence to work with people with dual disabilities increased after the training. Furthermore, there was more commitment to work collaboratively with other agencies to improve multidisciplinary support.

There are a number of characteristics of multidisciplinary service provision which are central to its effectiveness; namely, a close working relationship between professionals, regular meetings, case-specific liaison and appointment of a key worker to coordinate service provision for each child and family (Morton et al., 2003). All of these characteristics rely on effective communication, a topic which was frequently raised by participants in the present study. Breakdowns in communication between agencies were identified by both parents and service managers as one of the major challenges. Parent's commonly expressed frustration at the number times they are required to 'tell their story' to various service providers because means and methods of communication between services are not adequate. Service managers were also

sensitive to this frustration, and identified a lack of understanding about what other agencies provide as a major knowledge gap which should be addressed. Greater understanding of the scopes of practice of other services should stop families being referred to multiple providers. It could also potentially shorten the assessment process. If the referring agency communicated information to the new provider using consistent and norm referenced assessment methods then multiple assessments of the same difficulties could be avoided. Sharing of information between agencies has received mixed reviews in the literature however there is a paucity of methodologically sound studies that have evaluated practical outcomes (Sloper, 2004). All parents expressed a need for a single avenue through which their support services could be accessed and co-ordinated. Single 'case' or 'key' workers have been advocated in the literature on multidisciplinary practice as a solution to this difficulty (Douma, Dekker, & Koot, 2006). Consistent with research, the findings of the present study suggest that effective communication is important for co-ordinating care across multiple service agencies. Equally, communication is also a crucial component of the relationship between service agencies and parents.

Collaboration between Parents and Services

A collaborative relationship between parents and service providers was identified as an indicator of the extent to which services were meeting the needs of children and families in the present study. For parents, a collaborative relationship meant that they felt able to communicate their needs to services providers and trust that the outcomes would be a joint decision in the best interests of the child and the family. An appreciation of the knowledge and expertise that parents have about their child has previously been identified as a component of collaborative relationships (Crawford & Simonoff, 2003; Pollock Prezant & Marshak, 2006). Challenges to

collaboration that were identified by parents in the present study were staff attitudes and limited knowledge of family circumstances. Families are the long-term caregivers for children with dual disabilities, whereas services are generally provided on a relatively short term basis. Therefore an understanding of family unit as a whole is an important component of service provision according to the families in the present study. This is consistent with past research, such as Douma et al. (2006) who concluded that service providers need to increase their responsiveness to family diversity. Service managers also described various characteristics of a collaborative relationship with families. A commitment to work together to implement interventions was identified as a key indicator of the extent to which the service can have a positive outcome. In summary, the findings of the present study highlight that engagement in a collaborative relationship is mutually beneficial for both parents and service providers.

Impact of Parent Attributes on their Engagement with Services

Parental ability to function as an advocate for their child appeared to partially determine the extent of their involvement with services in the present study. Families who had both the financial capacity to fund additional services for their child, and a higher degree of confidence to seek services, tended to report more involvement with services overall. A study which also sought the perceptions of family carers of children with disabilities reported a similar finding, stating that “more articulate middle-class families with financial and psychological resources are more likely to succeed than others” (McGill, Papachristoforou, & Cooper, 2006, p. 164). Parents in the present study frequently described their experiences of engaging with agencies with the aim of obtaining support services. Increased stress and frustration were identified as a common result of these advocacy interactions. Similar experiences have been reported in previous

research. For example, Faust and Scior (2007) studied the impact of dual difficulties on parents. The authors reported that parents' experiences of interaction with mental health agencies were characterised by a lack of opportunities for parents to communicate with service providers and feelings that they had not been listened to. Negative experiences whilst advocating for access to services appeared to impact on continued engagement with services according to the findings of the present study. The level of stress experienced by parents of children with dual disabilities has been found to be higher than that of parents whose children do not have such difficulties (Douma, Dekker, & Koot, 2006; Faust & Scior, 2007). The causes of stress for these families are likely to be complex. Parental variables, such as coping styles and ability to manage stress partially determine their ability to act as an effective advocate. However external factors, such as the receptivity of service providers to parent's advances for support, are particularly important for decreasing the stress associated with acting as an advocate. These factors were also identified in a study on caregiver stress conducted by Keller and Sterling-Honig (2004). The role of the parent as advocate was not frequently discussed by service managers in the present study. Where it was discussed, they expressed sensitivity to the challenges of the role but also described the difficulty their organisation experiences in meeting the expectations of parents within their scope and model of practice. In summary, the present findings suggest that there are a number of parent variables which influence the degree to which children and families become involved with services. Service providers should be aware of the potential for families to become disengaged from services as a result of these variables and implement strategies to facilitate more equal access.

Models of Practice

The scopes and models of practice that determine the type and content of support services provided to consumers were described by service managers. This theme was included under the super-ordinate theme ‘higher level influences on service provision’ in the results section. It is discussed separately here as it has significant implications for integration of dual disability services. The service managers who participated in the present study had an in-depth understanding of the models of practice for their service area and the criteria that children must meet to receive services. However, service managers also highlighted that because models of practice differ significantly between service providers for dual disability, support often becomes fragmented for children and families. This appeared to be especially the case for dual disability mental health services, where the models of practice for intellectual disability and mental health differ considerably (Jacobson, 1999; Moss, Bouras, & Holt, 2000). Furthermore, where there are emotional difficulties the avenues for support are even narrower because both special educational services and intellectual disability services are only funded to work with challenging behaviour. The divergences in practice models have been recognised in previous research with comparable populations. Hall, Higgins, Parkes, Hassiotis and Samuels (2006) identified similar conflicts in a report on the implementation of a new integrated dual disability service in the United Kingdom. Historically, both in New Zealand and overseas, there has been a separation between disability services and mainstream mental health services (Molony, 1993). While the deinstitutionalisation movement has obviously had positive outcomes for children with dual disabilities in terms of increased inclusion in society, the provision of adequate therapeutic and support services in the community has not necessarily followed (Jacobson, 1999). Clarification of the models of practice

and roles of service providers in all sectors is required so that a common understanding of who is responsible for each aspect of service provision is achieved. Such understandings have been identified as critical components of improving therapeutic and support services for people with dual disabilities (Moss, Bouras, & Holt, 2000). Parents will be in a much better position to understand what types of therapeutic and support services are available to their child with dual disabilities if the services themselves are able to communicate such information to them.

Evaluation of Pilot Methodology

A study with a mixed method (quantitative and qualitative) design was developed with a view to evaluating patterns of service provision, the extent to which the scale and nature of services are matched to the type and severity of children's dual difficulties, and the extent to which parent opinions match the type and content of service provision. The original three research questions, introduced at the conclusion of chapter two, were formulated to reflect this. Due to the small number of parent participants and therefore index children that could be recruited within the time constraints of the study, it was determined that sufficient data to evaluate the second and third research areas would not be obtained. Therefore, one of the aims of the present project was to pilot the proposed methods with a view to conducting a larger study which could make those comparisons in the future. An evaluation of those methods is presented in this section.

Two quantitative measures were employed in the present study to determine the type and severity of dual difficulties that the index children experienced. Adaptive functioning was assessed using the ABAS-II (Harrison & Oakland, 2003) whilst emotional and/or behavioural difficulties were estimated with the DBC (Einfeld & Tonge, 2002). These measures of adaptive

and problem behaviour were reliable and valid, thus it is likely that they provided an accurate indication of children's current difficulties. However, analysis of data from these measures reflected the researcher's initial concern that a small sample could not provide the range of scores required to evaluate the original research questions. For example, analysis of DBC scores indicates that the index-children in the present study were rated within a relatively narrow range. Three children did not actually reach the clinical cut-off TBPS score stipulated by the authors of the DBC although they had been previously identified by the service provider as experiencing such difficulties. Additionally, the highest TBPS was 57 which is not considered to reflect a severe level of emotional and/or behavioural difficulties, given that the ceiling TBPS is 126. Therefore, if accurate comparisons are to be made between type and severity of the dual difficulties that the child experiences and the level and intensity of therapeutic and support services provision, then a more representative sample with varying degrees of severity of dual disabilities would be required. A comparison with children with intellectual disabilities who do not experience emotional and/or behavioural difficulties could be a component of this. Given the difficulties experienced recruiting participants for the present study, the sampling frame may need to be widened to include children attending segregated special schools and more recruitment sources could be approached to obtain a representative sample.

Overall the semi-structured interviews employed in the present study appeared to be valid for eliciting information about therapeutic and support services. This is consistent with previous research evaluating the use of semi-structured interviews for obtaining information from participants from comparable populations. The interview structure used with parents enabled the researcher to efficiently obtain a relatively in-depth account of parent's perceptions and

experiences of therapeutic and support services. The initial and super-ordinate themes that were identified from the interviews with parents are relatively consistent with those identified in the research literature, therefore indicating that the structure was effective. This was also the case for the semi-structured interview used with service managers. However, if the scale and nature of such services are to be matched to the severity and type of children's dual difficulties and if parent perceptions of therapeutic and support services are to be matched to the extent of their rating of their child's dual difficulties, then it would be advantageous to also include a measure which is more quantitative in nature. This would enable a less subjective analysis of the second and third research questions as initially proposed. A questionnaire such as that developed by Douma et al. (2006), which assesses support needs, the extent to which they are met and the reasons why on a quantitative scale, could potentially be adapted for a future study. However for the purposes of the present study, which aimed to gain some understanding of the lived experience of support service provision from the perceptions of those directly involved, the methods facilitated the gathering of valuable information. Analysis of the transcripts of the semi-structured interviews using the methods and principles of Interpretative Phenomenological Analysis has produced findings which enable a useful evaluation of therapeutic and support services for children with dual disabilities and their families in Christchurch, New Zealand.

Study Limitations

The present study had several limitations. Recruitment of participants was significantly affected by a number of variables, including the time taken to gain initial access to participants and the time of year at which participant recruitment was able to occur. As a result of the variables

affecting this study, the number of parent participants recruited into the study was fewer than what the researcher originally intended. Therefore, to increase the validity of the present study the researcher introduced a degree of triangulation (Brantlinger, Jimenez, Klingner, Pugach, & Richardson, 2005) by obtaining perspectives about the extent to which service providers are meeting the needs of the target population from three service managers. The sampling strategy was predominantly purposeful, with only three parent participants from the first service provider being recruited through random sampling methods. Therefore, the participants in the present study may not be representative of the population of parents with children with dual disabilities and service providers who support the target population. Subsequently, the views expressed by participants may not be a representative indication of the population prevalence of the themes identified during analysis. Parents and service managers who did not participate could have expressed either differing or contradictory experiences. Therefore, a larger and more representative sample would be an important component of a future research project.

Another significant limitation also relates to the amount of data that was able to be obtained in the present study. Given the qualitatively based design of the current project, it would have been beneficial to gather more qualitative data from the participants involved. Qualitative methods frequently involve longer periods of engagement with participants over two or more sessions, or gather data using multiple methods (Creswell, 2003). Furthermore, literature on qualitative research methods in the disability field includes prolonged engagement with participants as a credibility measure (Brantlinger, Jimenez, Klingner, Pugach, & Richardson, 2005). The depth of the accounts of service provision could have been increased if such methods had also been employed in the present study. Unfortunately, data collection procedures in the

present study were restricted by time and resource constraints. This necessitated single interviews with each group of participants and use of checklist measures completed by parent participants as the sole determinant of the presence and severity of emotional and/or behavioural difficulties. More accurate identification of the difficulties experienced by index children could be facilitated through the inclusion of other assessment methods, such as an interview. School teachers and teacher aides for respective children would also be a valuable source of information about the presence of dual difficulties. In-depth information gathering from multiple informants is considered to be best practice for both research and clinical purposes (Carr & O'Reilly, 2007).

The literature on research practices in the disability field has increasingly recognised the benefits of close integration of the researcher and participants throughout the study process, because it facilitates research outcomes more applicable to the target population (Brantlinger, Jimenez, Klingner, Pugach, & Richardson, 2005; Russell, 2004). The participants in the present study were parents of children with dual disabilities rather than the children themselves. However, such a distinction is artificial because parents can also experience the disabling barriers inherent in society (Russell, 2004). In disability research with children it is widely recognised that the perspectives of parents are integral to applicable research outcomes (Russell, 2004). In the present study, parent participants were offered the opportunity to see the transcripts of the interviews and make any changes. However, it would have been preferable for them to have more involvement in the original planning and later analysis stages of the study. Inclusion of methods which facilitate a greater depth of information about service provision and more involvement of the target population during the course of the study should be an important consideration in a future project.

Accounts of the type and content of therapeutic and support services for each index child were obtained only from parent participants, and therefore may not represent the actual service received. Parent reports of service provision have been found to be reflective of their subjective experience and therefore are liable to contain inaccuracies (McGill, Papachristoforou, & Cooper, 2006). The inclusion of service managers as informants about how services are provided to the target population in Christchurch lent a degree of confirmation to parent's accounts however the influence of the subjective experience of both groups of participants must be recognised. A follow on study might employ multiple informants as a more objective method of obtaining service provision information, such as asking each of the child's service providers or obtaining details from file notes.

Conclusion and Recommendations

The present study found that parents and service managers have similar perceptions of the extent to which current therapeutic and support services in Christchurch meet the needs of children with dual disabilities. There were few areas where parents and service managers did not provide similar accounts of the current state of services. The super-ordinate themes that were common to both groups were based around the current state of resourcing, collaboration between parents and service providers, multi-agency services and the lack of clarity around pathways to services. Understanding of respective roles and models of practice were areas where the two groups diverged in their perceptions of the current state of service provision. Parents and service managers all affirmed that there are areas where current services for dual disability are meeting needs, however a number of therapeutic and support needs are currently inadequately met. The

intention of the present study was not to produce a set of findings which generalise to the entire target population. However, the findings which have been discussed form the basis of the following recommendations which could improve the experience of therapeutic and support services for children with dual disabilities and their families. Importantly, further research is required in each of these areas and questions stemming from the present research project are outlined last.

General Recommendations

1. Both national and local reviews of disability services are required in order to clarify the models of practice which will be used for children with dual intellectual disability and emotional and/or behavioural difficulties. Development of a coherent national model of care for children with dual disabilities, which stipulates the roles and responsibilities of each service sector, would be a valuable outcome of such a review.
2. To enable increased co-ordination of care across services multi-agency collaboration needs to continue to develop with guidance from higher level government ministries and governing bodies of organisations. Effective communication, both between agencies and between parents and agencies, will be a key component of successful co-ordination of care.
3. Pathways to therapeutic and support services for children with dual disabilities need to be clarified for both providers and consumers. Parental stress in the role of advocate, particularly at times of transition between services, could be decreased if accurate information about the type and frequency of available services was accessible and consistent.

4. Development of a single source from which to disseminate information to families about the therapeutic and support services available in Christchurch for children with dual intellectual disability and emotional and/or behavioural difficulties would decrease the confusion currently occurring for parents about where to seek support. Avenues through which children and families can link with others in similar situations were particularly important for parents in the present study as it decreased their feeling of isolation in the community.

Further Research Areas

1. There is a need to replicate the present pilot study with a larger sample in order to obtain more definite and representative findings.
2. The results of the present study indicate that there appears to be a number of children with dual disabilities who do not receive intervention from mental health services despite experiencing dual disabilities. The reasons why this may occur should be established so that more effective levels of service provision can be implemented for this group.
3. The current project focused on patterns of therapeutic and support services provision for children with dual disabilities being educated in mainstream schools, however a similar study including children who attend segregated schools would enable further evaluation of the patterns and potential links between type and severity of dual difficulties and service provision.

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Appendix A: Subject Recruitment Information Letter and Consent Form

**School of Educational Studies and Human Development,
University of Canterbury**

Service Provider
CHRISTCHURCH 8140

October 2007

Attention:

To Whom It May Concern,

My name is Katie Dent, and I am a student in the Child and Family Psychology Programme at the University of Canterbury. As a component of my master's course I am conducting a small scale research project under the supervision of Michael Tarren-Sweeney, Senior Lecturer in Child and Family Psychology.

The objectives of the current project are threefold;

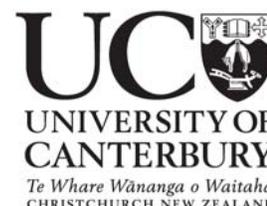
- To identify the patterns of therapeutic and support services provision for children with dual learning disability and mental health difficulties in Christchurch, New Zealand.
- To evaluate to what extent the scale and nature of such services are matched to the severity and type of children's learning and mental health difficulties.
- To evaluate to what extent parent opinions about therapeutic and support services are matched to the severity and type of children's learning and mental health difficulties.

At this stage I am seeking the opportunity to recruit approximately ten families who have children attending mainstream schools in Christchurch who have a mild to severe learning disability as well as mental health (including emotional and behavioural) difficulties. Parents of children will be asked to complete two psychological measures and a one to two hour semi-structured interview. I would appreciate it if your service would ask a number of families from your database who fulfil the above criteria whether they are willing to participate in the sampling stage of this research project. Please see the attached Parent Information Sheet.

The project has been reviewed and approved by the University of Canterbury Human Ethics Committee. All correspondence with families from your service will be kept strictly confidential whether or not they opt to take part in the study and all policies and procedures that your service follows to ensure this will be followed. Your involvement is purely voluntary. Please contact me by letter, phone or email to confirm your decision. If you have any questions please do not hesitate to contact me.

Thank you very much for your time and consideration.

Yours Sincerely



Katie Dent

Postgraduate Student

Ph: 027 696 0513

Email: kde25@student.canterbury.ac.nz

Project Supervisor : Michael Tarren-Sweeney

Ph: 03 364 2987 (ext 7196)

Email: michael.tarren-sweeney@canterbury.ac.nz

**School of Educational Studies and Human Development
University of Canterbury**

Project: Therapeutic and support services provision for children with dual learning disability and mental health difficulties in Christchurch, New Zealand.

Researcher: Katie Dent



**CONSENT FORM
FOR RECRUITMENT OF SAMPLING STAGE PARTICIPANTS FROM SERVICE DATABASE**

- I acknowledge that I have read the information letter attached and understand what is involved in this study.
- I _____ (name) on behalf of
_____ (Service name) agree to allow the researcher to seek participants from a list of randomly-selected clients from our database according to the policies and procedures already implemented in this service.
- I understand that all information gathered during the course of this study will be kept confidential and that all identifying details will be omitted.
- I understand that I can withdraw this service from this study at any stage.

Signature

Date

Appendix B: Parent Participant Information Sheet, Sampling Consent Form and Consent Form

School of Educational Studies and Human Development,
University of Canterbury



INFORMATION SHEET

January 2008

Dear Parents/Caregivers,

I am writing to request your involvement in a research project which aims to evaluate the support services provided to you and your child. My name is Katie Dent, and I am a Trainee Child and Family Psychologist at the University of Canterbury. As a part of my training I am conducting a small research project.

I have a particular interest in the occurrence of emotional and behavioural difficulties in children who have an intellectual disability. I have contacted you because your child has previously been identified as experiencing such difficulties and I would like to invite you to participate in this study. My research aims to identify what services are available to children and their families, and evaluate how they are meeting the needs of such children and their families.

Should you agree to participate I will ask you to complete:

- An assessment of your child's current level of functioning, this will involve the completion of two checklists (Takes approximately three quarters of an hour).
- A semi-structured interview with me in which parents will have the opportunity to discuss the services they are currently receiving and raise any issues or concerns. This will take approximately one to two hours. I would like to audio-tape this interview with your permission however, if you would rather not be audio-taped, your participation in this study would still be valued.

This project has been reviewed and approved by the University of Canterbury Human Ethics Committee. All information gathered about your child and family will be kept confidential to the researcher, with all identifying details omitted from the written report of findings. Your decision to participate or not will not be communicated to any other party. Information provided by parents and service providers will not be communicated with anyone other than the researcher and university supervisor. All identifying information will be destroyed at the conclusion of the research.

Should you agree to volunteer your participation in the current study please understand that you have the right to withdraw from the study and to decline to answer a question at any time. If you decide to withdraw from the study this will not affect the services currently provided to your child.

Thank you very much for your consideration of this request. If you are willing to participate or wish to know more please do not hesitate to contact me by phone or email.

Kind Regards

Katie Dent

Postgraduate Student

Ph: 027 696 0513

Email: kde25@student.canterbury.ac.nz

Project Supervisor:

Michael Tarren-Sweeney

Ph: 03 364 2987 (ext 7196)

Email: michael.tarren-sweeney@canterbury.ac.nz

**School of Educational Studies and Human Development
University of Canterbury**

Project: Therapeutic and support services provision for children with dual learning disability and mental health difficulties in Christchurch, New Zealand.

Researcher: Katie Dent



SAMPLING CONSENT FORM

I, _____, allow my name to be included in the sampling procedure for the above named project and give my permission for the researcher to contact me in regards to this project should my name be randomly selected.

My contact details are:

Address:

Phone: _____

Email: _____

Please indicate if you have a preferred method of contact:

Please note that your contact details will be kept strictly confidential to the researcher and will be destroyed once the sampling procedure is completed.

Signature

Date

Katie Dent
Postgraduate Student

Ph: 027 696 0513

Email: kde25@student.canterbury.ac.nz

Michael Tarren-Sweeney
Project Supervisor

Ph: 03 364 2987 (ext 7196)

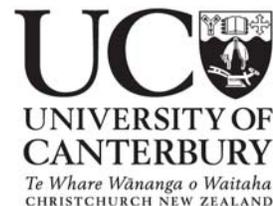
Email: michael.tarren-sweeney@canterbury.ac.nz

PLEASE RETURN THIS FORM IN THE REPLY PAID ENVELOPE PROVIDED

**School of Educational Studies and Human Development
University of Canterbury**

Project: Therapeutic and support services provision for children with dual learning disability and mental health difficulties in Christchurch, New Zealand.

Researcher: Katie Dent



PARENT/CAREGIVER CONSENT FORM

- I acknowledge that I have read the information sheet attached and understand what is involved in this study. I have been given the opportunity to ask the researcher any questions about the study.
- I understand the study will be written up in the form of a report and submitted for marking at the University of Canterbury.
- I understand that all information gathered during the course of this study and included in the written report will be kept confidential to my family, the researcher and the supervisor, and that all identifying details will be omitted. No information provided by parents or service providers will be communicated to the other party.
- I do/do not (circle applicable one) give permission for the parent interview to be audio recorded and understand that the tapes and accompanying documents will be destroyed at the conclusion of the research.
- I understand that I can withdraw from this study, including withdrawal of any information I have provided, or decline to answer a question at any stage.
- I _____ (parent/caregiver's name) agree to participate in this study.
- I have explained this study to my child, they understand what is involved and agree to have information disclosed about them by the parent/caregiver named above.
- I *do/do not* (circle applicable one) give my permission for the researcher to contact the service providers listed below to obtain information about the services (type and content) that my child has received in the past year.

Service Providers:

-
-
-
-
-

Signature (Parent)

Katie Dent
Postgraduate Student
 Ph: 027 696 0513
 Email: kde25@student.canterbury.ac.nz

Date

Michael Tarren-Sweeney
Project Supervisor
 Ph: 03 364 2987 (ext 7196)
 Email: michael.tarren-sweeney@canterbury.ac.nz

Appendix C: Service Provider Information Sheet and Consent Form

School of Educational Studies and Human Development,
University of Canterbury

January 2008

Attention: Manager

To Whom It May Concern,



My name is Katie Dent, and I am a student in the Child and Family Psychology Programme at the University of Canterbury. As a component of my master's course I am conducting a small scale research project under the supervision of Michael Tarren-Sweeney, Senior Lecturer in Child and Family Psychology.

I have a particular interest in learning disability and the common co-occurrence of mental health difficulties in such children. The study I am conducting is an extension of this interest in which I aim investigate three objectives:

- To identify the patterns of therapeutic and support services provision for children with dual learning disability and mental health difficulties in Christchurch, New Zealand.
- To evaluate to what extent the scale and nature of such services are matched to the severity and type of children's learning and mental health difficulties.
- To evaluate to what extent parent opinions about therapeutic and support services are matched to the severity and type of children's learning and mental health difficulties.

In order to answer part of my research question I would like to conduct a semi-structured interview with you in order to gather information about the type and content of the service you have provided and how you perceive they are able to currently meet the needs of children with dual disabilities.

This project has been reviewed and approved by the University of Canterbury Human Ethics Committee. All information about your service will be kept strictly confidential and no identifying information will be included in the analysed data or final report. All policies and procedures that your service follows to ensure privacy laws are upheld will be followed by the researcher.

Should you agree to take part in this study I will make a time convenient to you to come and conduct the interview.

Thank you very much for your time and consideration.

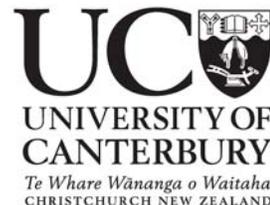
Yours Sincerely

Katie Dent
Postgraduate Student
Ph: 027 696 0513
Email: kde25@student.canterbury.ac.nz

Project Supervisor:
Michael Tarren-Sweeney
Ph: 03 364 2987 (ext 7196)
Email: michael.tarren-sweeney@canterbury.ac.nz

**School of Educational Studies and Human Development
University of Canterbury**

Project: Therapeutic and support services provision for children with dual learning disability and mental health difficulties in Christchurch, New Zealand.



Researcher: Katie Dent

SERVICE PROVIDER CONSENT FORM

- I acknowledge that I have read the information letter attached and understand my involvement in this study. I have been given the opportunity to ask the researcher any questions about the study.
- I understand the study will be written up in the form of a report and submitted for marking at the University of Canterbury.
- I understand that all information gathered during the course of this study and included in the written report will be kept confidential and that all identifying details will be omitted.
- I understand that the policies and procedures already in place to uphold privacy laws in this service will be followed by the researcher.
- I _____ (name) from
_____ (Service name) agree participate in this study.
- I understand that I can withdraw myself and/or this service from the study at any stage, including withdrawal of any information I have provided.

Signature

Date

**Katie Dent
Postgraduate Student**

Ph: 027 696 0513

Email: kde25@student.canterbury.ac.nz

Project Supervisor:

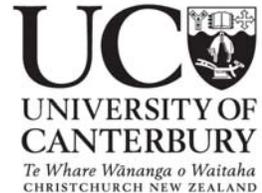
Michael Tarren-Sweeney

Ph: 03 364 2987 (ext 7196)

Email: michael.tarren-sweeney@canterbury.ac.nz

Appendix D: Semi-structured Interview Topics for Parents

School of Educational Studies and Human Development,
University of Canterbury



Parent Interview

Individual Child

Services child has received in the past year including:

- Educational
- Health (Medical and Psychological/Psychiatric)
- Welfare
- This information will need to include the names of the services, date contact with the service started, length of time in contact with the service.

Overall information

- Areas you feel that your child is well supported in, reasons.
- Areas that you do not feel your child is well supported in, reasons.
- Areas for improvement of the services received overall.

Educational services

- Recap what services the child is receiving if necessary.
- Aspects of educational provision the parent is happy with.
- Areas for improvement.
- Child's concerns about educational provision.

Health (Medical)

- Recap what services the child is receiving if necessary.
- Aspects of medical provision for child the parent is happy with.
- Areas parent can identify for improvement.
- Child's concerns about their medical needs.

Health (Psychological)

- Recap what services the child is receiving if necessary.
- Aspects of provision for your child's mental health needs parent is happy with.
- Areas for improvement.
- Child's concerns about their needs for psychological support.

Welfare

- Recap what services the child is receiving if necessary.
- Satisfaction with support provided by New Zealand's welfare system for children with disabilities.
- Areas for improvement.

Family

- Level of support in role of caring for child.
- Aspects that have been helpful.
- How family could be better supported.
- Sibling support.

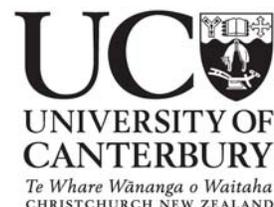
Appendix E: Semi-structured Interview Topics for Service Providers

Service Provider Interview

Name of Service:

Date and Time:

Length of career in service:



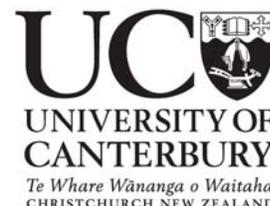
- 1) What does this service provide for children with dual disabilities?
- 2) What are your thoughts about how this service does meet the needs of such children and families?
- 3) What are your thoughts about how this service could better meet the needs of children and families?
- 4) What do you think parents would say about how this service is or is not meeting the needs of their child?
- 5) What is your evaluation of how the services work together to meet the needs of children and families?
- 6) How could they work better together?

Appendix F: Confidentiality Agreement for Transcriber

Confidentiality Agreement for the Transcriber of

the Research Study Entitled:

Therapeutic and support services provision for children with dual intellectual disability and emotional and behavioural difficulties in Christchurch, New Zealand.



Researcher: Katie Dent

My role as the research transcriber has been outlined to me by the researcher.

At all times the research information (tapes and transcripts) will be inaccessible to other persons. The researcher has assured me that she will debrief me following transcribing to address any issues that transcribing may bring up for me.

Most importantly, I understand and agree to keep the information I hear and type in the course of transcribing confidential to the researcher and myself. I understand that this requirement is life long and extends beyond my involvement in the project.

Full Name: _____

Signature: _____

Date: _____

Researcher's Signature: _____

Date: _____

Appendix G: Human Ethics Approval Letter

HEC Ref: 2007/93

20 July 2007

Ms Katie Dent
School of Educational Studies & Human Development
UNIVERSITY OF CANTERBURY

Dear Katie

The Human Ethics Committee advises that your research proposal “Service provision for children with a dual diagnosis of an intellectual disability and emotional and behavioural disorder in Canterbury, New Zealand” has been considered and approved.

Yours sincerely

Dr Michael Grimshaw
Chair, Human Ethics Committee

Appendix H: Participant Recruitment Log

Project: Therapeutic and support services for children with dual intellectual disabilities and emotional and/or behavioural difficulties in Christchurch, New Zealand.

Researcher: Katie Dent

Tues 24th April 2007; Talked with staff member at College, she suggested that a personal at a Special Education could assist with accessing participants for study.

Mon 21st May 2007; Email to second supervisor and asked whether participants could be recruited through SP.

Wed 23rd May 2007; Met with staff at SP, able to provide access to participants that meet the inclusion criteria for the study however it would be necessary for me to get Human Ethics Approval before the Research Office would approve the research.

15th June 2007; Human Ethics Proposal submitted to committee for approval.

17th July 2007; Contacted Human Ethics Committee Secretary to ask about progress with ethical approval. Said decision due next week.

Sat 21st July 2007; Human Ethics Approved. Talked to SP about process for obtaining their approval for recruitment of participants through the database.

6th August 2007; Emailed research office regarding participant recruitment.

13th August 2007; Team leader for research, replied to email I sent asking questions about the participant recruitment process.

16th August 2007; Emailed Michael (Supervisor) to check that I had answered the questions appropriately.

21st August 2007; Replied to email indicating that I would respond to questions once I had advice from my supervisor.

31st August 2007; Emailed reply to questions.

7th September 2007; Emailed updated documents to research office for final approval.

13th September 2007; Received email that they had approved my request for participants and the appropriate documentation has been sent to the manager at SP.

2nd October 2007; Emailed research office to follow up as to whether had heard from Manager at SP about the status of my request for participants. She replied to contact them directly.

2nd October 2007; Rung and left message on managers phone inquiring about status of request.

2nd October 2007; Emailed both managers asking about status of request for participants.

9th October 2007; Emailed original contact at SP asking how to best contact manager about the status of my participant request.

18th October 2007; Staff member replied with suggestion that I contact PA for manager to make a time to speak with him.

22nd October 2007; Rung PA for manager and scheduled a time to speak with him on the 30th of October 2007.

30 October 2007; Phone call with manager to organise participant recruitment process. Organised to drop letters to his PA on the 31st which should go out by end of week.

Thursday 15th November 2007; Phone call with PA who indicated that the 20 letters had not yet gone out, but would try to get them out next week.

Week 19th to 23rd November 2007; First lot of letters sent out to potential participants.

Friday 30th November 2007; Met with Caroline Mohr, my second supervisor. Asked again about possibility of recruiting some participants through them however because of ethical processes required by the health board which take time this is not a viable option.

Week 3-7th December 2007; Organised for a second lot of 20 letters to be sent out due to only receiving four responses back from previous lot, of which only two were eligible for the study. Talked to PA about ensuring sampling criteria applied to the people sent out letters.

3rd December 2007; Went to interview first participant however they did not meet the study criteria.

4th December 2007; Interviewed first participant.

14th December 2007; Interviewed second participant, however then decided that they did not meet the criteria for the study.

17th December 2007; Interviewed third participant.

Tues 18th December 2007; Because only one reply from second lot of letters so far, left a message on PA's answer phone asking about possibility of sending out a third lot of letters before Christmas.

19th December 2007; Emailed original contact at SP asking whether it would be possible to send out another 20 letters in early January.

19th December 2007; Replied to say that PA was unwell but back now and suggested I ring her.

21st December 2007; Emailed asking about possibility of getting letters out, indicated that it would not be possible until January. Dropped in letters to PA so that these can hopefully be sent out in early Jan.

9th January 2008; Rung SP 2 about the possibility of recruiting some participants through them, was put in touch with staff member who said they would discuss it at team meeting on Fri 11th Jan.

Rung SP 3, possibly able to help but person who could help away on leave until 14th Jan so left message to call me back.

Rung two participants to ask whether they knew of any families who may fit the study criteria. One had a contact whom she would contact and ask to email me.

10th January 2008; Dropped in further information to SP 2 about the study.

Interviewed fourth participant in study.

11th January 2008; Rung SP 2 about possibility of participants, indicated that they were not sure yet whether anyone would qualify but would contact me early next week.

Talked to a Phd student conducting research in the adult disability field about whether she knew of any services or families that may be able to participate.

14th January 2008; Emailed original contact at SP 1 asking whether letters could be sent out, replied that PA was still away and the other administration staff were not aware of any instructions from her regarding the whereabouts of the letters I had dropped in or about sending them out.

Rung and left a message for manager of SP 1 asking to ring me about participant recruitment.

At the suggestion of SP 2 I rung SP 4 to see whether they might be able to help with recruiting participants, however because they do not directly deal with families they indicated that they would not be able to help.

Talked with supervisor who said to try as many services as I can for more participants and to log phone calls and emails.

Rung the SP 5 to ask about possibility of recruiting participants through them however the director is away until Weds 16th Jan.

Rung and left a message for SP 3 about possibility of them helping me out with recruitment of participants.

Talked with Phd student who suggested a parent support group. She was also going to talk to a contact of hers.

Rung and left a message for SP 2 inquiring about whether or not they may be able to help with recruitment of participants.

Talked with Parent Co-ordinator at SP 6 about possibility of accessing participants through them. She will contact some parents whom may fit the criteria for the study and ask whether they would consider taking part in this study. Once she has their consent to pass on contact details to me she will ring back.

Emailed manager of SP 1 further to earlier phone call asking to follow up on third lot of letters to be sent out.

15th January 2008

Meeting with supervisor; discussed situation with the smaller number of participants recruited than expected. Decided to continue recruiting participants but also to try and talk to 3 or 4 service providers to gain an understanding of their perception of the services they provide to children with dual disabilities as this would provide a degree of triangulation. Also that this dissertation will be treated as a pilot of a potential Phd project and the strengths and limitations of the research design will be critiqued as a part of the findings and discussion.

16th January 2008

Emailed second supervisor about proposed to changes to study. She agreed that this was a good option and also suggested a staff member of her service provider to interview.

Emailed three potential staff of service providers with information about the study, asking whether they would consent to be interviewed.

Talked with Parent co-ordinator who suggested two families who had agreed for me to contact them about taking part.

17th January 2008

Rung and organised an interview with a service provider.

Rung one of the two families suggested by the parent co-ordinator and organised an interview time and date.

Phone call received from a service provider in response to email, organised time and date.

18th January 2008

Phone call received from parent co-ordinator who suggested another family who had agreed for me to contact them about taking part. Rung and made time to go and see them.

21st January 2008

Interview with SP 1.

23rd January 2008

Interviews with two families

24th January 2008

Interview with SP 2.

28th January 2008

SP 3 contacted me to set up interview date and time.

1st Feb 2008

Interview with SP3 completed.

No more attempts to recruit participants were made after this date to allow time for data analysis and report write-up to occur.