

“I Feel Like I Count”

Flexible Support Packages in a Real Partnership

The report of a consultation with families and staff about
the key features of the Making a Difference and Early
Choices Programs operated by
Monograph Series No. 33

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Mackillop Family Services
2005

QUOTATIONS USED IN TITLE

*“The best part I like about this program is that **I feel like I count**. Like most Mums looking after kids, you begin to feel invisible after a while. I don't feel invisible. I know I've got back-up.”*

Mother of 15 year old child with Down syndrome and autism

*“My Family Services Coordinator always thinks of things that will help. Not that she makes my choices. She suggests options and discusses consequences. She is honest and transparent. I've always felt empowered. **It's a real partnership.**”*

Mother of 6 year old child with autism and an intellectual disability

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FOREWORD

When a child with a disability is born into a family, all members of the family will be required to give something extra of themselves. These families are also entitled to receive extra support from the wider community, to help share the challenges and to help respect the preciousness of every child.

The report has been commissioned in the context of possible changes to services in the light of the current State Disability Plan. It provides telling information gathered from a consultation with families who participate in MacKillop Family Services Making a Difference and Early Choices programs. These services are designed to support families with a child with a disability in a variety of ways. We are pleased to hear that families appreciate these services, particularly because they are flexible, resourceful and individualised, and we hope that this report will ensure the continuation of this service model in the future

We particularly thank the families who participated in the research, and the project worker, Nerida Mulvey, who undertook the interviews and prepared the first drafts of the report. We also thank Karyn Hobday and Kath Barry, the program managers of MacKillop's disability services in Barwon and Melbourne, who facilitated and guided the project, and John Honner and Jacki Urquhart, from MacKillop's Practice and Policy Unit, and Graham McKern, from MacKillop's Development Unit, who prepared the report for publication.

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EXECUTIVE SUMMARY

MacKillop Family Services provides Flexible Support Packages (FSPs) to children with a disability, aged from birth to 18 years, and their families in Geelong and in Melbourne. Two of the FSPs provided by MacKillop Family Services, the Making a Difference and the Early Choices programs, are the focus of this report.

Priority Strategy Plan 1 of the State Disability Plan (State Disability Plan Implementation Plan, 2002-2005) recommends the introduction of “an individualised planning and support model that is based on people’s needs and the choices that they make about their lives”. There is a risk that the implementation of this plan may have the unintended consequence of closing down existing programs which already meet these goals. MacKillop Family Services asserts that the Making a Difference and Early Choices programs are examples of an individualised planning and support model.

MacKillop Family Services commissioned this consultation in order to document the strengths of the Making a Difference and Early Choices programs and to describe the features which identify them as examples of an individualised planning and support approach. By placing in the public arena views from recipients and practitioners involved with these programs, and by gathering objective information about these programs, MacKillop Family Services intends to make a contribution to policy discussion about service delivery models and ensure that proven, effective services are maintained.

This consultation is fortuitously in harmony with a recent report commissioned by the Department of Human Services titled “Review and Redevelopment of Support for Children with a Disability and their Families” (Wagstaff, 2004). Wagstaff’s report formulates principles to “guide the redevelopment of support for children with a disability and their families”. MacKillop Family Services believes their Making a Difference and Early Choices programs have a high degree of congruence with the principles described in Wagstaff’s report. This consultation demonstrates the congruence.

The most recent guidelines for the Making a Difference and Early Choices programs were produced under the banner of Flexible Support Packages in 2003. The goals, objectives and service description for Flexible Support Packages remain essentially the same as those described in the guidelines provided when the Making a Difference and the Early Choices Programs were first established in 1994. It is testimony to the strength of these programs that their key features have endured over more than 10 years.

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This consultation was conducted from December 2004 to March 2005, gathering both qualitative and quantitative data. A reference committee guided the consultation to ensure that it would be useful, accurate, feasible and ethical, and to ensure that it adhered to the project brief and the proposed timelines. The qualitative data includes interviews with a sample of families engaged in the programs and interviews with the practitioners involved in delivery of these programs. The quantitative data includes numbers of clients, gender, age, family type, disability type, program initiatives, location, and needs register (waiting list) numbers.

The consultation demonstrated that the Making a Difference and the Early Choices Programs are characterised by seven key features – flexibility, responsiveness, individualised, family centred, resourceful, case managed, and innovative – as explained in the following points.

1. *Flexibility.* The relationship between the family and the Family Services Coordinator (FSC) acknowledges both individual differences between families and differences in need at different times. The frequency of contact, the nature of contact and the duration of contact are examples of the flexibility of the relationship between the family and the FSC. In addition, there is flexibility in the make-up of packages provided to families. The intensive and short term packages are able to respond to the needs of families at key transition times and around other critical events in the family life cycle.
2. *Responsiveness.* The family needs constitute the criteria for access to packages and discretionary funding. The programs are particularly responsive to families in crisis, families who are isolated, and families who are unsuccessful in accessing mainstream services.
3. *Individualised planning and support.* These programs demonstrate individualised planning and support by tailoring services to suit individuals and families, enabling families to have choice in decisions affecting their lives, and respecting that families know what they need and want. Families are encouraged to take time to develop their plans, and the plans can be easily adjusted if needed. Families can be creative in developing plans because the guidelines for using discretionary funds provide for the purchase of both traditional and non-traditional goods and services. The management of the discretionary fund by the service provider in a transparent way offers choice and control to families about decisions affecting their lives.
4. *Family centred.* A family centred approach, reflecting MacKillop’s overarching practice framework, is key to every aspect of the programs’ operation.
5. *Resourceful.* Discretionary funds are used in a resourceful way to maximise their usefulness for families. In addition, another appreciated aspect of these programs is their success in finding additional funds and resources to support families.
6. *Case management.* Case management includes the provision of information, co-ordination of services, family support, advocacy, planning for the future

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and referral to other services. Families expressed throughout the consultation the value placed on these important elements of case management.

7. *Innovative.* Interviews demonstrate the importance within these programs of “program initiatives” for individual families, as well as innovative group activities and the add-on value which they provide for families.

The families interviewed in this consultation expressed their strong support for both the Making a Difference and Early Choices programs operated by MacKillop Family Services. They appreciated the key components of these programs, as described in the Findings section of this report (see p. 15 below). Similarly, the practitioners employed by MacKillop Family Services who were interviewed in this review expressed strong support for these key components of Making a Difference and Early Choices.

There is also a high level of congruence between the Findings section of this report and the research findings and literature review provided in “Review and Redevelopment of Support for Children with a Disability and their Families” (Wagstaff, 2004).

Given such strong support for these two Flexible Support Packages, two questions arise. If the Flexible Support Packages model is such a valued model for service delivery to people with a disability, why are significant resources being allocated to development of new models of service delivery? Secondly, what will be the impact of new models of service on the Flexible Support Packages? The responses to both questions will be of great interest to supporters of best practice in disability support services in Victoria.

In the light of these findings, we recommend that a comprehensive evaluation of Flexible Support Packages programs, in particular Making a Difference and Early Choices, be undertaken by the Department of Human Services. The evaluation should consider the program, in particular, as models of individualised planning and support, as cost effective, and as effectively supported by case management.

ABBREVIATIONS

DHS	Department of Human Services
FSC	Family Services Coordinator
FSP	Flexible Support Packages
IP&S	Individualised Planning and Support
ISS	Intensive Support Service Package
STAP	Short Term Assistance Package

1. INTRODUCTION

1.1 MacKillop Family Services

MacKillop Family Services was established in 1997 as a refounding of seven long established Catholic community service organisations. MacKillop is a specialised provider of child, youth and family services to some of the most marginalised families in Melbourne and Geelong. Key areas of support include family and community services, specialist education, out of home care, disability services, and support for former residents. This work is coordinated through over 90 services and the efforts of some 380 staff and a further 400 volunteers.¹

MacKillop’s vision, as stated in its 2005-2010 Strategic Plan, is for “an organisation where people are our priority and our values are evident in our process, relationships and practice. As such

- our practice will be strongly focussed on the needs and aspirations of the children, young people and families we work with, emphasising partnership, participation, and advocacy;
- our staff, carers and volunteers will be valued, informed, supported and connected across the organisation;
- we will promote strategies which build and strengthen communities.

In developing the organisation we are committed to

- the achievement of professional standards and accountability in our work;
- seeking innovation, creative change and new opportunities;
- growing through research, innovation, partnership and invitation;
- being true to our heritage and creating an identity of our own.”

Many of the children and young people supported by MacKillop Family Services have complex and challenging needs. In some cases they may have exhausted all other support services, residential or education programs. Currently, on any one night, around 90 children and young people are in residential care with MacKillop Family Services and another 150 children are in foster care or specialised home based care placements. Each year around 700 families in the Western suburbs of Melbourne are assisted through a range of early intervention and preventive family support services. Each year nearly 250 children and young people who are at risk of dropping out of mainstream schooling, or who are not attending school at all, attend MacKillop’s education and training programs in Melbourne and Geelong. Over the course of the year nearly 400 families facing the challenging task of raising a child with a disability receive support through MacKillop’s programs in Melbourne and Geelong. MacKillop Family Services also provides a Heritage and Information service for former residents of the orphanages associated with its founding agencies. The Heritage and Information service provides access to records, documents, photographs and memorabilia, and assists past residents and their families to trace personal and family histories and associations. Around 250 new enquiries are made of this service each year.

¹ For more information on MacKillop Family Services see www.mackillop.org.au.

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1.2 Disability Programs provided by MacKillop Family Services

MacKillop Family Services provides a range of services for families with children with disabilities: in Geelong through Bayview Disability Services, and in Melbourne through MacKillop Disability Services (Metro). These services include:

1. Flexible Support Packages (FSPs)
2. Case Management services by contract: for example Family Choice Program (Royal Children’s Hospital), Transport Accident Commission, Support and Choice Initiative (Department of Human Services)
3. Respite and recreation
4. Accommodation – Special Support Unit (Williamstown), Family Options (long term home based care with volunteer caregivers)
5. Administration of Continence Subsidy Scheme
6. Parent and information support.

Two of the Flexible Support Package programs provided by MacKillop Family Services – the Making a Difference and the Early Choices programs – are the focus of this consultation.

The Making a Difference program is funded by the Disability Services Division, Department of Human Services. It aims to support families caring for school aged children with moderate, severe and profound disabilities and high support needs through the provision of case management and discretionary funds. The Early Choices Program is also funded through the Disability Services Division, Department of Human Services. It aims to support families caring for children with moderate, severe and profound disabilities aged 0 to 6 years through the provision of case management and through discretionary funds.

1.3 Purpose of the Consultation

This consultation was undertaken in the context of the Priority Strategy Plan 1 of the State Disability Plan Implementation Plan, 2002–2005, which recommends the introduction of “an individualised planning and support model that is based on people’s needs and the choices that they make about their lives” (see section 2, “Context”, immediately below).

Anecdotally, the experience of families and practitioners at MacKillop Family Services is that the Making a Difference and Early Choices programs are individualised, are flexible, are responsive, and are family centred. While both programs were evaluated by the Department of Human Services soon after their establishment, in 1996 and 1997 respectively, no evaluations have occurred in the past eight years. For the past five years MacKillop Family Services has had mechanisms in place to ascertain client feedback about the quality of the programs it provides. The organisation decided to undertake this consultation in order to identify the key features of these programs from families’ perspectives and to consider whether they constituted models of individualised support and planning. MacKillop Family Services wanted to ensure that the features identified in these programs were acknowledged and preserved while new models of individualised support and planning were being developed.

The goals of the consultation were to

- (a) identify the key features of Flexible Support Packages (FSPs) from the perspective of families in receipt of these services and to consider whether the FSPs match the characteristics of individualised support and planning;

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- (b) consider the congruence between the families’ perspectives and those of practitioners employed within the programs;
- (c) ensure that the key features of FSPs are acknowledged and preserved in any new models of individualised support and planning.

2. CONTEXT

2.1 History and Development of Flexible Support Packages

The Establishment of the Making a Difference Program

In earlier service delivery for people with disabilities in Victoria, families were actively encouraged to place their children in institutional care. Since the 1980s, with growing awareness of the rights of all individuals to be active members of the community with access to the same opportunities as other members of society, the Victorian Government has closed large residential facilities for people with disabilities and developed a new range of services.

It was within this context that, in 1991, the Disability Services Branch of the Department of Human Services undertook program development work to improve the care of children aged 5 to 18 years with intellectual disabilities.

Pilot programs were established in the northern Melbourne metropolitan region in 1992 and in the southern and western metropolitan regions in 1993. The pilot programs were titled “Making a Difference: Placement Prevention Program for Families of Children with an Intellectual Disability”. The program aims were:

- To increase the opportunities for children with an intellectual disability aged 5-18 years to remain living with their families, rather than being placed in out of home care;
- To develop more appropriate alternatives (socially, emotionally, developmentally) and more cost effective alternatives to residential care of children with intellectual disability;
- To decrease both the practical burden of care and the stress associated with the care of a child with a disability.

The pilot programs were successful in achieving their aims. In early 1994 the target groups were expanded to include children 5 to 18 years with a physical or sensory disability or a serious chronic illness in each region of Victoria. The Making a Difference program was established at St Anthony’s Family Centre in Footscray (now called MacKillop Disability Services Metro) in December 1994 and at Mercy Family Care in Geelong (now called Bayview Disability Services). These agencies became part of MacKillop Family Services when the new organisation was formed in 1997.

The stated objective of the Making a Difference program was “to assist families to care for their moderately, severely and multiply disabled children at home by implementing and operating a flexible and responsive range of services that meet their additional support needs. Enhancement of quality of life and independence of children, young people and their families is the ultimate goal” (Making a Difference Program Service Plan, 1994/1995).

This objective was to be achieved by the appointment of Family Services Coordinators (FSCs) to work in partnership with families to identify their needs, to provide case management, and to prepare expenditure plans for the use of discretionary funds. The discretionary funds were to be used to top up existing services to families or to create new services for a group of individuals with a similar service need. It was emphasised that every effort should be made to access services through locally based mainstream agencies or to use such agencies as an auspice, in preference to the establishment of specialist services. There

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was acknowledgement that most families would require a long-term service, even though the intensity and type of service may vary over time. A small proportion of families, on the other hand, might require only a one-off service. Eligibility to receive the discretionary fund was subject to a means test, though exceptions could be made.² Between \$5,000 and \$10,000 could be allocated to a family without approval from the Regional or Head Office of the Department of Human services, with potential for a further \$20,000 with appropriate approvals.³

The Development of the Making a Difference Program

An external evaluation of the Making a Difference Program was conducted in February 1996 (McVicar and Reynolds, 1996). The evaluation found the program to be effective in achieving its goals. The evaluators commented that, “the strength of the approach lies in

- its focus on supporting the whole family
- working collaboratively with families to identify how they can best be assisted and then developing individually tailored responses to meeting their needs
- the ability to provide case management support, and on a long term basis where necessary; and
- access to additional funding which can be used in a diversity of ways.”

(McVicar and Reynolds, 1996, xii)

Importantly, the evaluation noted that the Making a Difference Program was “primarily a long term case management service working with families with the highest needs for support” (McVicar and Reynolds, 1996, xi). The subsequent guidelines (Making a Difference Program Guidelines, 1997) acknowledged the need for long and short term support by categorising families according to their capacity to self manage and then by identifying service providers targets for each category.

Further recommendations from the McVicar and Reynolds evaluation, relating to staffing levels and to support, supervision and training of Family Services Coordinators, were also implemented shortly after its completion. These improvements served to strengthen the program and instigated its extension to adults (18-65 years) with moderate, severe or profound disabilities and their families or other carers.

In 2000, concerned by the number of families that were unable to access its Making a Difference programs, MacKillop Family Services conducted research into the state-wide needs registers (waiting lists) for the Making a Difference Program (Bearup and Honner, 2000). According to this research, “evidence gathered from workers, providers, families and Department of Human Services reports demonstrates that the number of families being provided for by Making a Difference Program 5-18 is only a fraction of those in need”. The report recommended an increase in funding for the program and greater flexibility in the application of these funds. “If providers were given greater discretion in the allocation of

² “Families with a combined family income of \$60,000 are not eligible to access the discretionary fund component of the program although the case management is available to them” (Draft Making a Difference Program Statement and Guidelines, November 1994, at s3.4).

³ Decisions on expenditure require the following approval;

- up to \$5,000 “once off” and recurrent. Decision rests with agency.
- \$5000 - \$10,000 “once off” and recurrent. Region to agree. The region may give responsibility to one officer or may establish a small group that can be convened quickly to discuss the application.
- Over \$10,000 “once off” and recurrent. Application to Disability Services with final decision from the Assistant Manager, Child, Adolescent and Family Services Unit.

As a broad guide, maximum expenditure per family per annum should be limited to \$30,000 (Draft Making a Difference Program Statement and Guidelines, November 1994).

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brokerage funds, some families which are largely able to self manage could be given immediate one off assistance packages and their situation would be less likely to become critical for want of any support.” (Bearup and Honner, 2000, 1)

The introduction of Short Term Assistance Packages (STAP) in 2000 responded to the concerns expressed in the MacKillop report. STAPs helped not only to alleviate the pressure on the Needs Register maintained by each service provider, but also provided an option for families with capacity for self management who wanted only short term, intermittent support.

The Establishment of the Early Choices Program

In contrast to the Making a Difference program, Early Choices was initiated by the Specialist Children’s Services, Family Services Branch of the Department of Human Services, in 1994, using funds from the Community Support Fund. The program was developed to support families with children under the age of 6 who have a severe disability and high support needs. Early Choices was designed

- to provide supports which will assist families to care for their children at home;
- to provide a flexible range of support tailored to meet individual families’ needs; and
- to provide flexible support packages to families of children under school entry age with severe disabilities and high support needs (including those dependent on technology) such as home based intensive behaviour intervention, in home care and alternative family based respite (Early Choices Program Draft Guidelines, 1995).

These objectives were to be achieved in a similar manner to the Making a Difference program. An Early Choices Coordinator was to be appointed to work in partnership with eligible families to assist them in identification of their support needs. Funds were available to purchase respite and support, to train carers and to purchase equipment. Discretionary funds would not be used when existing service options were available. Eligibility for the Early Choices program was not means tested. It was envisaged that the role of Family Services Coordination could be delegated to another service provider by negotiation. Up to \$5000 could be allocated to any one family with agency approval, \$5,000 to \$8,000 with Regional DHS approval and more than \$8,000 with Head Office DHS approval.

The Early Choices program was delivered through 14 regionally based, non-government agencies. Most were family support agencies that administered a range of other programs in addition to Early Choices. The Early Choices program was established at MacKillop Family Services in Footscray in 1997. In the Barwon region, the Early Choices Program is facilitated by an agency other than MacKillop Family Services.

The Development of the Early Choices Program

An evaluation was conducted during the pilot phase of the Early Choices program, concluding in November 1997. The evaluation found the program to be an innovative early intervention support program that demonstrated considerable benefits for families. The features of Early Choices that were highlighted in the evaluation included:

- its focus on family centred practice as a way of describing the partnership between practitioners and families;
 - the use of case management as the major strategy to operationalise the family centred approach;
 - the responsiveness of the program to the concerns of families;
 - that discretionary funds can be used in flexible ways because they are not tagged.
- (McLeod Nelson and Associates, 1997)

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The McLeod Nelson evaluation noted problems in relation to procedures and protocols that were resolved during the pilot phase, and problems in relation to understandings about the meaning of concepts such as case management and family centred practice that needed to be addressed through a targeted professional development program. There was some discussion as to whether the program should stand alone within a wider service system of similar programs, or whether it should provide a level of service delivery targeted at families with children with the most severe disabilities within an integrated service system. The Department of Human Services then undertook a process of consultation and debate about the future of the program, culminating in a Ministerial announcement that it would continue in its current form.

The Early Choices Guidelines (1998 and 2000) and the Specialist Children’s Services Program Standards (1998) provided increasingly sophisticated definitions of the concepts of case management and family centred practice. These documents also attempted to address the Government’s concerns about the lack of criteria for the use of the discretionary funds. “The concern expressed through the pilot phase by some central and regional departmental staff is whether Early Choices should supplement or even replace other programs that are available, particularly when the family’s needs are not necessarily related or a direct consequence of the child’s disability.” (McLeod Nelson and Associates, 1997)

The Current Guidelines for Flexible Support Packages

The most recent guidelines for the Making a Difference and Early Choices Programs were produced in 2003. The Making a Difference, Early Choices, Continuity of Care and Family Choice Programs were at that time gathered together as Flexible Support Packages under the auspice of the Disability Services Division, Department of Human Services. The 2003 Guidelines are significant because they are taken to implement a priority strategy from the newly developed State Disability Plan “to reorient disability supports to better respond to people’s needs at different ages and stages in their lives” (State Disability Plan, 2002-2012).

The 2003 Guidelines highlighted several key features of Flexible Support Packages, notably the family centred approach, whereby a Family Services Coordinator works in partnership with individuals, families and carers to identify support needs and develop a care and expenditure plan, using case management and a discretionary fund. The Guidelines also established the Short Term Assistance Packages introduced into the Making a Difference Program in 2000 (and not previously available within the Early Choices Program) as part of the Flexible Support Packages. Further, greater prominence was given to the development of a Care Plan which “will be developed to document agreed priorities and responsibilities” (Flexible Support Packages Guidelines, 2003, 9). This concept was consistent with the individualised planning and support model referred to in the State Disability Plan (State Disability Plan Implementation Plan, 2002-2005). Emphasis was given to the fact that the discretionary fund was discretionary and that families had no entitlement to funding: “The allocation of discretionary funding is to be based on identified needs, the service provider’s assessment and availability of funding” (Flexible Support Packages Guidelines, 2003, 9). Finally, a policy for closure with families was described. This new feature emphasised the availability of the packages for families on short, medium or long-term bases. The Guidelines thus incorporated the Family Centred Practice approach, the Best Practice Principles for Children 0-18 with disabilities and complex care needs (endorsed by the Department of Human Services in 1995), and the Permanency Planning Principles that underpinned the delivery of child, young person and family disability services in Victoria.

It is noteworthy that the goals and objectives and the service description for Flexible Support Packages remain essentially the same today as those described in the initial guidelines provided when the Making a Difference and the Early Choices Programs were established in 1994. It is a testimony to the strength of these programs that the key features of the programs have endured over a 10 year period.

2.2 State Disability Plan 2002-2012: Individualised Planning and Support

The Victorian State Disability Plan 2002-2012 was launched by the then Minister for Community Services and Housing, Bronwyn Pike, on 3 September 2002. It outlined the Victorian Government’s vision for the future and designated strategies for realising this vision. Its approach reaffirmed the rights that people with a disability have to live and participate in the community as citizens of Victoria, regardless of age or disability. The Government promised a whole-of-government approach to disability services. Government departments were to strengthen working partnerships with people with a disability, parents, families and carers, support providers, local governments and local communities, to build a Victoria that works together to fulfil the aspirations of people with a disability.

Instead of focusing on specific programs, such as personal care, or merely responding to crises, the Government wanted disability services to support people with a disability in flexible ways, based on their individual needs, so that each person could live the lifestyle that they wanted to lead. Nevertheless, the Government recognised that many support providers were already providing supports to people with a disability in innovative ways that maximised people’s opportunities to participate in the community. The Government stated that it would be looking at ways to acknowledge these innovations and to share them with others, so that everyone could benefit from the changes that were taking place.

The State Disability Plan identified its Priority Strategy 1 as “Reorient disability supports”. This meant changing the way that the disability support system operated as a whole and developing a framework that enabled disability supports to be more flexible, to work with people with a disability as partners, to respond to people’s individual needs, and to support them to pursue a lifestyle of choice.

The State Government thereby promoted an individualised planning and support framework to enable disability supports to be tailored to people’s individual needs. This approach recognised the importance of earlier planning and support to achieve the best possible outcomes at all ages and stages of a person’s life – as children, young people, adults, and as people with a disability. Most importantly, this approach would put people with a disability at the centre of support delivery, so that service providers would work together with people with a disability and their families as equal partners to enable them to exercise choice in getting the support they needed to pursue their own lifestyles.

2.3 Wagstaff Review of Support for Children with a Disability

The Government’s new policy direction could have a negative effect on existing Flexible Support Packages in so far as they may be viewed as belonging to an earlier service system. A significant document in relation to this present consultation, therefore, is Margaret Wagstaff’s recent report, commissioned by the Department of Human Services, titled “Review and Redevelopment of Support for Children with a Disability and their Families” (Wagstaff, 2004). Wagstaff’s report offered principles to “guide the redevelopment of support for children with a disability and their families”. They are:

- The best care of children is provided by a supportive family within a supportive local community;
- Early intervention and early planning and support are most likely to be effective in assisting children and supporting parents and families;
- Support for children with a disability and their families should primarily be provided through local, mainstream generic and specialist services;

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- Disability workers should adopt a family centred approach to support and strengthen the whole family;
- Regular respite care in home and out of home is an essential aspect of the disability supports required to enhance family functioning and alleviate pressures on family;
- Planning and support for children with a disability should take the form of an individualised service plan that focuses on identifying flexible formal and informal supports to respond to individual and family needs;
- Disability supports should be age appropriate and appropriate to the particular disability and behaviours being addressed;
- Flexible responses should be tailored to the particular needs of Aboriginal children and their families and those from culturally and linguistically diverse backgrounds;
- Government and community service organisations should foster partnership, collaborative relationships, best practice in service delivery, continuous quality improvement, service viability and productivity;
- Communities should be strengthened and encouraged to be more welcoming and inclusive of children and young people with a disability and their families.

As shall be shown in the sections that follow, this present consultation found these principles already operating in MacKillop Family Services’ approach to the Making a Difference and Early Choices programs. Further, the families in this consultation affirm many of these principles.

2.4 Support and Choice Initiative

The Victorian Department of Human Services, in line with the State Disability Plan 2002-2012, is currently implementing a new approach to supporting people with disabilities. The Individualised Planning and Support approach (IP&S) aims to enable a person with a disability to direct their own life as much as possible. With the support of a facilitator or planner, each person identifies their particular life goals and works out a plan to achieve these goals. The plan considers the person’s individual abilities, aspirations and needs within their network of family, friends and community, and identifies the range of the supports necessary to make the plan work. While the plan will often include government-funded support, it also focuses on wider and more community-oriented options.

For families of children with a disability, the plan focuses on supporting the family as well as meeting the child’s specific needs. This initiative, known as Support and Choice, is currently being put into practice in each of the DHS regions across the Victoria. Support and Choice is funded through new growth funding allocated to Disability Services through the State Budget and does not replace existing Disability Services programs.

The Support and Choice process, as outlined by DHS, follows three steps:

- **Step 1: Put a plan together.** Together with a facilitator, people develop a plan that reflects what they want to do, how they want to do it, considers the support that needs to be put in place and what options are available.
- **Step 2: Put the plan into action.** The facilitator works with the person to identify how the supports might be funded, whether through Disability Services or another source, and who will be responsible for organising arrangements. If parts of the plan require funding from Disability Services, the facilitator will submit a funding proposal to the DHS regional office. Any parts of the plan funded by Disability Services will be provided through an Individual Support Package. Depending on the person's situation, existing supports and available funding, all or parts of the

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plan can be put into action. This may involve some help from family, friends, carers or other people involved in the person’s life.

- **Step 3: Review of the plan.** The review should look at what has been achieved so far, confirm what is working well and revise goals where necessary. Where possible, supports may be rearranged to better achieve these goals.

2.5 Concluding Comment

This review of the establishment of Flexible Support Packages and the development of a new approach to individualised planning and support (the Support and Choice Initiative) demonstrates that both the Flexible Support Packages and the Support and Choice Initiative have much in common and are not necessarily incompatible. As the following sections demonstrate, MacKillop Family Services provides Flexible Support Packages in a way that allows families to make individual choices that meet their particular needs. Furthermore, the Flexible Support Packages model allows for consistency of case management and ready connection with a range of services.

3. METHODOLOGY

3.1 Background to the Consultation

The proposal to undertake this consultation was initiated by the two Disability Services Program Managers and their respective Regional Directors within MacKillop Family Services. It was approved by the Policy and Programs Committee of MacKillop Family Services, a sub-committee of the Board of Directors, in August 2004. A project brief was subsequently prepared and a project officer appointed. The project officer was recruited externally to MacKillop Family Services.

3.2 Methodology

The consultation was conducted from December 2004 to March 2005. It was both an advantage and a disadvantage that the consultation was undertaken over the summer school holiday period. The advantage was that families tended to be available to be interviewed and the disadvantage was that parents were distracted by the demands of their children at home. It is possible that the timing of the consultation may have impacted upon the sample of families who agreed to participate in the review, though no evidence for this was found.

There were qualitative and quantitative aspects to the consultation. The qualitative aspects comprised interviews with a sample of families in receipt of packages from the Making a Difference and Early Choices programs operated by MacKillop Family Services, and interviews with the practitioners involved in delivery of these programs. The quantitative aspect comprised data collection about all families in receipt of packages from these programs, including families receiving Short Term Assistance (STAP) packages and families receiving Intensive Support Service (ISS) packages. Data on families on the Needs Register for these programs was also included. The data collected included information about the age and gender of the child, the nature of his/her primary and secondary disability, the composition of the household where the child lives, housing, the child's primary caregiver, the purposes for which discretionary funds are used, and involvement in “program initiatives” facilitated by MacKillop Family Services. This quantitative data is reported in section 5 below (see p. 27).

The primary aim of the consultation was to learn from families about their experience of the Making a Difference or Early Choices programs operated by MacKillop Family Services. All families in receipt of Intensive Support Service packages were invited to participate voluntarily in an interview with the project officer by a letter signed by the Program Manager of Bayview Disability services or Disability Services (Metro) (Appendix A). The invitation included a plain language statement describing the purpose of the consultation (Appendix B). Two adult movie tickets were offered as an incentive and acknowledgement to families who participated in the consultation. It was hoped that approximately 20% of the families receiving services from the programs would respond to the request and that the participants would be representative of both the programs and the range of disabilities possessed by children receiving services. The families were interviewed by the project officer in their home, by telephone or at a group meeting at MacKillop Family Services. The interviews were semi structured and their duration ranged from 1 to 1.5 hours (see Appendix C for interview questions). The interviews were recorded and later transcribed by the project officer. Families gave consent for their comments to be included in the report (Appendix D).

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A reference committee was appointed to guide the consultation to ensure that it was useful, accurate, feasible and ethical, and to monitor the findings to ensure that it adhered to the project brief and the proposed timelines. The reference committee met on three occasions during the consultation period.

3.3 The Participants

The sample of families who participated in the consultation

Representatives from thirty one families (caring for thirty three children with disabilities) currently receiving Flexible Support Packages participated in an interview with the project officer:

- Fourteen families receiving Flexible Support Packages from Disability Services (Metro) and seventeen families receiving Flexible Support Packages from Bayview Disability Services were interviewed. This represents 11% of the Melbourne families and 32% of the Geelong families who receive packages through these programs.
- The majority of families interviewed are recipients of the intensive Making a Difference program package. Of the thirty one families interviewed, twenty nine children receive Intensive Support Service Making a Difference program packages, two children receive Intensive Support Service Early Choices Program packages, one receives a Short Term Assistance Making a Difference Program (STAP) package and is on the Needs Register for an Intensive Support Service, and one child receives a Continuity of Care package. Two families have two children each in receipt of Making a Difference Program Intensive Support Service packages.
- Seventeen interviews were conducted in family homes, nine were conducted by telephone and five were conducted in a group or individually at the office of Bayview Disability Services or Disability Services (Metro). Of the seventeen home visits conducted, eight were located in the City of Greater Geelong, three in the City of Melton, two in the City of Altona, two in the City of Wyndham and two in the City of Maribyrnong.
- Interpreters were used on three occasions, twice on home visits and on one occasion in a telephone interview.
- The person representing the family in the interview was primarily the mother of the child with a disability. Twenty seven mothers participated in the interviews. However, three grandmothers, six fathers and one twelve year old child with a disability also participated.
- Two of the families interviewed have previously received a package from a service provider other than MacKillop Family Services.

Characteristics of families participating in the consultation

Of the thirty one families interviewed,

- The primary disability of the majority of children is intellectual. Eighteen children have an intellectual disability, seven children have autism spectrum disorder, and eight children have a physical disability.
- Fifteen families have a sole carer. Eighteen families have two adult carers.
- The majority of children with a disability have one or more siblings living in their household: eight children have no siblings in their household, thirteen children have one sibling, nine children have two siblings, two children have three siblings, and one child has more than three siblings.

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- The ages of the children with a disability range from three to seventeen years. Three children are six years or under, fifteen children are seven to twelve years or younger, and fifteen children are thirteen to eighteen years.
- The majority of children with a disability are male. Twenty four children are male and nine children are female.
- The majority of children with a disability are the youngest child in the family. Eleven children are the oldest, fourteen children are the youngest and eight children fall into the category of “other”.
- The majority of families have received intensive Flexible Support Packages for more than three years. Nine families have received a package for less than one year, one family has received a package for less than two years, three families have received a package for less than three years, and eighteen families have received a package for more than three years. One family is currently on the Needs Register (waiting list) and has received short term packages only. The majority of families received short term packages while on the Needs Register awaiting intensive packages.

The sample of MacKillop practitioners who participated in the consultation

One of the objectives of the consultation was to learn from each of the practitioners involved in the delivery of the Making a Difference and Early Choices programs about their experience working with families in receipt of packages from these programs. These interviews with practitioners provided information to the project officer about the programs and a context for interviews with families. The interviews and consideration of the material gained from them also enabled the Project Officer to consider the congruence between families’ perspectives and staff employed within the respective programs. The interviews were semi structured and their duration was approximately one hour in duration (see Appendix E for questions used in these interviews). The interviews were recorded and transcribed by the project officer.

Twelve practitioners from MacKillop Family Services were interviewed by the project officer. The Program Managers and Team Leaders from both Services are included in this number:

- The professional qualification of the majority of the Family Service Coordinators (FSCs) interviewed is in social work. Five of the staff are social workers, two are qualified in welfare studies, two are qualified in nursing, one in psychology, one has a generic tertiary qualification and one has a specific counselling qualification.
- The length of time that FSCs have worked at MacKillop Family Services ranges from several months to 10 years.

4. FINDINGS: KEY FEATURES OF FLEXIBLE SUPPORT PACKAGES

As a result of the interviews conducted with families in receipt of Flexible Support Packages (FSPs) from the Making a Difference and Early Choices programs, seven key features were identified: FSPs are flexible, responsive, individualised, family centred, resourceful, provide case management, and are innovative. These characteristics are described in the seven sub-sections below. The direct quotes from family members provide authenticity, richness and depth to the findings.

4.1 Flexible Support Packages are *flexible*

A feature of these programs is their flexibility. There is flexibility in the relationship between the family and the FSC which acknowledges both individual differences between families and differences in need at various times. Frequency of contact, nature of contact and duration of contact are all flexible, depending on a family’s requests. In addition, there is flexibility in the style of package provided to families. The intensive and short term packages are able to respond to variations in need of families, especially at key transition times and other critical events in the family life cycle.

Families often adjust the goals and tasks detailed in their annual care plans during the year. This feature of the packages is mentioned frequently by families, who appreciate the acknowledgment of the inevitability of change and circumstance in families’ lives, especially when there is a child with a disability in the family. If a particular need is not able to be addressed due to cost factors, then usually the Family Services Coordinator (FSC) will discuss the situation with the family, endeavour to source the funding required, and the care plan will be altered accordingly.

Quotes:

“The main thing is they are flexible. You’ve got this set amount and you go through it at the start of the financial year. You go through your goals and aims and that sort of thing. But you can’t foresee everything. You can have a rough idea but if things come up, new problems or whatever they will always look for ways to change it or look for ways to move your funding or swap things around .It’s fantastic.”

Mother of 11 year old child with epilepsy and intellectual disability

“It seems that MacKillop calls on a needs basis. Our agreement is roughly monthly.”

Mother of 15 year old child with intellectual disability

“A good thing about it is they don’t bother us very much. Our FSC rings us once every two or three months and that’s enough. We don’t need someone to call us every week. When we have troubles we will call her. We manage ourselves most times. Our FSC notices that. I am very proud that we can manage ourselves.”

Father of 14 year old child with cerebral palsy

“Occasionally, my FSC will say ‘Let’s go and have a cup of coffee or lunch. I’ve got a spare half hour and I’ll come and pick you up.’ It’s normalising it.”

Grandmother of 8 year old child with autism

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“We have a case management plan. We look at where we’ve been and how we are going and at times I just hand it over when I’m tired or something’s been too much.”

Mother of 9 year old child with intellectual and physical disabilities

“I think that it’s very good that I can use the money for other things – not just respite like some other places. At another place we go, if we don’t use the money for respite, then we lose the money. But it’s not in our culture to use respite care.”

Father of 12 year old child with autism

4.2 Flexible Support Packages are *responsive*

A second feature of Flexible Support Packages is their responsiveness. Access to the Making a Difference and Early Choices Programs is primarily based on a family’s assessed needs. The programs are particularly responsive to families in crisis, families who are isolated from extended family, friends and community, and families who have difficulty accessing mainstream services. Due to the nature of ISS packages, trusting relationships are developed between families and FSCs. Sometimes families have struggled without support for many years or have had negative experiences with other support services. Families are supported to develop and implement their care plans.

Throughout the consultation families expressed the importance of programs responsive to their needs especially when an emergency arises. The capacity of the service responding to concerns and requests from families was seen as vital and was seen by families as an acknowledgement that a child with a disability can have major, immediate and unpredictable impacts on a family’s functioning. Families continually emphasised the importance of the responsiveness of the programs to their needs. The programs acknowledge that families are in the best position to assess their needs and make decisions about the services and supports they require.

Families talked about the importance of security, of feeling that the program would support them as long as they needed that support. Some families who have experienced the closure of a “relied upon” support service expressed anxiety about relying too heavily on the long term nature of any program.

The operation of the programs at MacKillop Family Services is supported by streamlined administrative systems which promote responsiveness. The duty system, telephone message system, ready availability of a member from the Disability Services team, and direct payment of accounts were all mentioned by families during the consultation.

Quotes:

“The best part I like about this program is that I feel like I count. Like most Mums looking after kids, you begin to feel invisible after a while. I don’t feel invisible. I know I’ve got back-up.”

Mother of 15 year old child with Down syndrome

“I like that I have control. MacKillop just gives you a hand and steers you in the right direction.”

Mother of 9 year old child with intellectual disability and physical disability

“I need a case manager who is long term who knows what my program is.”

Mother of 13 year old child with intellectual disability

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“I like that I’m guaranteed funding for him till he’s 18. It’s a relief.”

Mother of 8 year old child with intellectual disability

“This way everyone seems to get a fair cut. Everyone gets assessed on what their child’s needs are.”

Mother of 16 year old child with autism and intellectual disability

“The fact that it’s long term helps. You think that you’re not alone but at the same time you don’t want to pin too much hope on it because you think that it could all be taken away. I don’t look at it as a long term thing. At the back of my mind, I think, ‘If I don’t have MacKillop, what will I do?’ ”

Mother of 11 year old child with epilepsy and intellectual disability

“They don’t make judgements that this person looks socioeconomically OK so they don’t need the service. There is understanding about the decrease in standard of living. I might look OK from the outside. I might know where my next meal is coming from but there is still a huge change in the present for me and what the future holds. Not all services do that.”

Mother of 15 year old child with intellectual disability

“Even when my FSC isn’t there, I can always talk to someone else on the Team if I need something. They’ll get back to me. They never, ever say no.”

Mother of 9 year old child with intellectual and physical disabilities

“When my FSC has been away, there’s always someone there. I feel supported by the organisation.”

Mother of 11 year old child with intellectual disability and epilepsy

“Their phone system is good. The way they treat you as a human being. If the phone is going through to voice mail, they are polite enough to take the call back and ask if you want to leave a message.”

Mother of 15 year old child with intellectual disability

“There is another service I use where you have to put your case to them and they go away and have a meeting and decide if you fit their criteria. It doesn’t feel like that at MacKillop.”

Mother of 11 year old child with intellectual disability and epilepsy

“I tend to know what I want. I know what my daughter needs. I just haven’t got the money.”

Mother of 13 year old child with intellectual disability

“I started swimming with my son to help him lose weight but I injured my knee. Now the carer picks him up from school and swims with him. I meet them at the pool after their swim and she helps me shower and dress him.

Mother of 15 year old child with intellectual disability and autism

“We wanted to move closer to services that could help us. MacKillop paid for the removalist. It saved me so much work. Moving a house can be such a major thing. We couldn’t have paid for it ourselves. It was really practical and really helpful.”

Mother of 13 year old child with epilepsy and intellectual disability

“I never had the money to pay for things up front so I was able to get companies to invoice MacKillop directly.”

Mother of 13 year old child with intellectual disability

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“I broke my leg two years ago and MacKillop provided extra care because I couldn’t care for my 6 year old grandson.”

Grandmother of 8 year old child with autism

“My daughter’s bill for continence products is between \$1300 and \$1500 a year and the government gives me \$450.00. The Making a Difference program tops that up.”

Mother of 11 year old child with cerebral palsy

4.3 Flexible Support Packages are *individualised*

Because programs are flexible and responsive, they are also able to focus on the individual. Families report that this is indeed the case. FSPs are tailored to suit each individual and his/her family. The development of the “care and expenditure plan” is a further feature of this model. The consultation heard from families that they felt respected, that Family Service Coordinators were aware that families usually know what they need and ensured they had choices in decisions affecting their lives. Families considered the programs acknowledged the individual differences of each family and promoted creativity in the planning and implementation of care plans. They saw the Making a Difference and Early Choices programs as broad and non-prescriptive.

Quotes:

“I don’t think there would be two families here receiving exactly the same type of service. The money isn’t categorised or put into boxes saying families with disabled children need this type of service. I object strongly to the services that fund according to what stereotypically most families need, where the majority rules.”

Mother of 15 year old child with intellectual disability

“Every family needs different things. There’s not a set cut and dried thing that families need.”

Mother of 13 year old child with physical disabilities

“I don’t really know what I want. When she first started I was too scared to ask for anything because I’d been brought up to be seen and not heard, to never ask for things. Plus, I’d never had a child with a disability before so I didn’t know really know what’s out there and what’s available.”

Mother of 17 year old child with intellectual disability

“The worst time was when our son started school. Every day a new crisis would pop up. We didn’t know from day to day what would happen. Our FSC came up with all sorts of ideas of what was needed. We didn’t know.”

Mother of 11 year old child with epilepsy and intellectual disability

4.4 Flexible Support Packages are *family centred*

It was evident from the consultation that families placed considerable importance on, and showed appreciation of, the family centred approach of the programs. This approach acknowledges the complexity of families and the impact of decisions about one family member on the lives of other family members. Families partner with their FSC to plan “provision of appropriate services, the on-going development of the child and support for the family” (Flexible Support Packages Guidelines, 2003,19). Examples of the family centred focus of the programs include assistance with provision of, and referral to, services for other members of the family as well as for the child with a disability. Such services may include attendant care, respite, educational programs, therapeutic assessment, counselling and allied health services. Families particularly like the “program initiatives” designed to support the whole family, such as activities for parents, siblings and families.

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Quotes:

“It’s not just about the child, like respite houses are.”

Mother of 17 year old child with autism

“My FSC is always on the ball and out there to help not just my son but the whole family including my daughter. My FSC often gives me suggestions about my daughter who left home ... and became pregnant.”

Mother of 15 year old child with intellectual disability and autism

“Only my second son has a package but most of the things that I get for him benefit the other boys. It’s not strict that it has to be for one child in the family.”

Mother of 15 year old child with Down syndrome

“My son went to the siblings group. He’s too old for that now but he really liked it. He has two siblings with a disability and he didn’t feel like he fitted into his family because he was different.”

Mother of 15 year old child with Down syndrome

“My FSC shows interest in my other children and my mother and grandmother who live with us. She notices if Grandma is tired.”

Mother of 10 year old child with intellectual disability

“My second son has a disability but my daughter has been quite troubled. My FSC supported me when I made a notification to Child Protection. She was clear that we should work in a way that would be good for everyone in the family.”

Mother of 6 year old child with autism

“Two of my sons and I stayed in a house at the beach for a couple of nights so we could all have a break from our child with a disability. He has autism and can be totally full on. They arranged respite for him in our house. We had an amazing time at this beautiful place.”

Mother of 6 year old child with autism

“My FSC encouraged me to look at doing a course. I love the mixture of people at school. I’ve been stuck at home for so long. My study is going to be beneficial in the future but it’s also a sanity saver for me now.”

Mother of 17 year old child with intellectual disability

“Our youngest child was in hospital for a long time and we didn’t have time to help our older girls with their homework. Our FSC arranged to take them to tutoring class and would pick them up each week and drive them there. Education is very important to our family and we are very grateful to her.”

Father of 8 year old child with Down syndrome

“Last year they paid for a weekend away for my husband, my daughter who doesn’t have a disability and me. We went to the snow. It was great for my daughter because she’s 12 and we’d never been away just with her. She misses out on so much. There’s no way that we’d have been able to do something like that with our son. MacKillop paid for his respite care while we were away.”

Mother of 13 year old child with epilepsy and intellectual disability

“We use the money towards the expense for our annual holiday. We have been to different places. Next week we are going to hire a caravan for a few days in Torquay. The holiday is

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very important because we have time to relax and we can look at a different view. Everything is the same at home all the time. The whole family will go on holiday. We are already packed and we aren't going for a week!”

Father of 8 year old child with Down syndrome

4.5 Flexible Support Packages are *resourceful*

An essential, important characteristic of FSPs highlighted by families is the ability and capacity of Family Services Coordinators to respond and resource the needs that families expressed. Sometimes the resourcing depended on the knowledge, experience and skills of the FSC, other times it depended on the discretionary funds available or the ability of the FSC to secure other additional funding. Sometimes it was a combination of all these factors. Families emphasised the value of FSCs seeking funds from other sources. There were many examples given by families of the use of discretionary funds and additional funding to purchase non traditional services and supports that had beneficial short term and long term outcomes for families. They included:

- equipment to promote exercise and independence such as trampolines, treadmills, memberships to gymnasiums, three wheeler and modified bicycles, swing sets;
- items to entertain the child with a disability such as videos and players, DVDs, connection to the internet, movie tickets (and provide respite to families);
- personal items such as glasses;
- household items such as dryers, washing machines, air conditioning and heating, fans, furniture, fridges, microwaves;
- educational services and equipment such as computers, school books and tutoring;
- recreational activities for the child with a disability such as swimming, bowling, music therapy, horse riding, gymnastics;
- services that nurture and support the whole family or a particular family member such as holidays, massages, physiotherapy, counselling, alternate therapies;
- equipment to help with transport such as vehicle modification not funded by the Aids and Equipment Program, transport to appointments;
- funds to top up equipment and home modifications only partially funded by the Aids and Equipment Program such as bathrooms, ramps, hoists, three wheeled strollers for adult;
- items to protect the child with a disability such as gates, fences, window grills, bedding;
- emergency assistance with daily living expenses such as petrol vouchers, pharmacy items, grocery vouchers, Telstra vouchers, car repairs and servicing, car registration, house removal, housework.

Quotes:

“We use the funds for respite for our son. The carer comes and takes him out with other kids with a disability. They do things together that we can't do and he learns to relate to other children and how to behave. It's hard to give these kids a normal experience. They don't have a peer group at school.”

Father of 17 year old child with autism

“My son is autistic and it is difficult to occupy him. MacKillop got him a trampoline one Christmas. Other times they got him a treadmill and a swivel chair.”

Mother of 17 year old child with intellectual disability and autism

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“MacKillop helped me with an industrial strength clothes dryer. My son is autistic and he likes to wrap the clothes around the washing line and they never dry.”

Mother of 17 year old child with intellectual disability and autism

“MacKillop replaced the cover on the couch that my son sits on. I don’t know where I would be able to get this sort of funding if it weren’t for MacKillop.”

Mother of 7 and 11 year old children with autism and intellectual disability

“My son is 13 and he has epilepsy and an intellectual disability. His whole life is movies and videos. He lives his life through videos. My FSC bought us a TV and video. It’s been such a great thing. I put it in my bedroom and he goes in and lies on the bed and is calm and takes time out.”

Mother of 13 year old child with epilepsy and intellectual disability

“Last year I was very ill. I had a major operation. Our FSC was fantastic. She got us extra funding to help us through. I was off work for 3 months. We had help with ironing and transporting the children to school and their activities.”

Mother of 13 year old child with intellectual disability

“Last year MacKillop bought a lamb’s wool mattress protector with magnets in them. They are good for pain. Our son has cerebral palsy and tightens up during winter but with the mattress protector he sleeps better and doesn’t get as tight.”

Mother of 9 year old child with intellectual and physical disabilities

“This year my FSC gave me a lovely Christmas hamper. I’ve never had one of them before. I thought it was wonderful.”

Mother of 5 year old child with Down syndrome

“My FSC went to a Trust and explained about my son’s diet and they gave me a cheque to help pay the mortgage. She’s also gone through another group and got a scholarship for my other children for school camps and expenses.”

Mother of 8 year old child with epilepsy and intellectual disability

“Three years ago, on Christmas Eve, my fence blew over. Having no fence was a real issue because my son is autistic and has an intellectual disability. At the time he liked to stare at the sun so he’d follow it around the house and walk backwards onto the road. MacKillop put it to a service club to fund the fence.”

Mother of 17 year old child with intellectual disability and autism

“We had to take our daughter to the Royal Children’s Hospital for two operations. When we arrived there we noticed that the car was leaking from the radiator. We didn’t have the \$600 to fix it so we rang our FSC and she said, the money’s available, use it. It was just what we needed at the time. We couldn’t have driven home. I’m not sure where the money came from.”

Mother of 12 year old child with physical disability

4.6 Flexible Support Packages provide Case Management

Case Management is provided by Family Services Coordinators to families who receive intensive support service packages. Case Management can include: provision of information on available services and resources; coordination of services; family support; advocacy; planning for the future; and referral to other services. Families during the consultation expressed the value they placed on the receipt of timely and accurate information about generic and disability specific services and aids and equipment. They talked about the value

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of the assistance with the coordination of the purchase of goods and services. Advocacy in certain situations at certain times from Family Services Coordinators was expressed as important by families. FSCs advocate for families in all aspects of family life but particularly with the education, health, housing, income security and disability service systems. Furthermore families talked about the value of referrals their FSCs made to other services to meet their needs. Families stressed the importance of the emotional support they received from their FSC. They placed great value on the relationship they had with their FSC.

Quotes:

On provision of resources

“Case management eases the burden and shares the load. You can’t put a dollar amount on having someone you can call who knows your family and knows the system out there and saves you the distress of making the next phone call. It’s invaluable to be able to ring one person and say I can’t do this anymore and for them to say we’ll get some support in there for you.”

Mother of 18 year old child with intellectual disability

“It’s good to speak with someone who deals with situations that come up on a daily basis who can give us ideas or strategies drawing from her experience with other families.”

Mother of 9 year old child with intellectual and physical disabilities

“My FSC made numerous phone calls and wrote letters when we were looking for a van to transport my daughter in and looking for a hoist to lift her. She was a fantastic resource. If I couldn’t find anything or do anything, I’d call her because she’d know or she would find out. I’m good at finding out things now, but I wasn’t good at it then. You are thrown in the deep end.”

Mother of 13 year old child with physical disability

“It’s not just about the money. My FSC knows how to ring around and she knows who to ring. My son was having trouble getting in and out of the bath and I was frightened that he would slip and fall on me. If I were injured the family would sink because I’m the only adult in the house and two of my children have a disability. The FSC arranged for someone to come and put bars in.”

Mother of 15 year old child with Down syndrome

“Our family likes to go bike riding together but at the moment my husband or I have to stay home because our son isn’t safe to ride on roads or bike trails. We want to get a tandem bicycle. Our FSC’s going to help to find it and will purchase it out of our funding. She’s taking pressure of me by doing this because I’m not very good at asking for help or taking handouts.”

Mother of 9 year old child with intellectual and physical disabilities

On coordination of services

“I need people like my FSC to help me through the maze.”

Mother of 10 year old child with intellectual disability

“My FSC usually rings me when she knows there’s a curriculum day coming up. She knows how busy I am and takes some of the worries from me. I was getting so disorganised for a while. There was so much to keep under control.”

Mother of 17 year old child with intellectual disability

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“During the holidays my FSC sits down with me and encourages me to organise respite for my son. I’m over it. I’m sick of it. I ask her to come over and we’ll do it together. I am good at coordination but every now and then I run out of puff.”

Mother of 16 year old child with intellectual and physical disabilities

“My grandson has been abominable at school. The Principal had a meeting of everyone involved with him in the first 6 months and 35 people turned up. From then on each year our FSC has organised a meeting at school with the services to see how we can help one another. It’s for coordination and information sharing and to let everyone know my grandson is important to a lot of people.”

Grandmother of 8 year old child with autism and intellectual disability

“I forget lots of things but my FSC knows where I am at. She rings and asks how I went with this or that. She knows where I am at more than I do. She keeps track of what’s happening.”

Grandmother of 8 year old child with autism and intellectual disability

On family support

“My son would be in an institution if it weren’t for the support I receive from my FSC. He is 24/7.”

Mother of 8 year old child with epilepsy and intellectual disability

“They are my lifeline. Without their help I doubt if I’d be here today. I can’t thank them enough. I give them a call and 9 times out of 10 they’ll be straight over. I have a lot of issues and I don’t have anyone to help me. “

Grandmother of 16 year old child with cerebral palsy

“I receive a lot of support from my FSC. I am one of those people who gets very wound up. It could be a few little things happening or the slightest little thing that tips me over the edge. You can ring up and talk to her and she’s got a way of calming me down. It might be the aids at school who think they know best or problems with other members of the household.”

Mother of 9 year old child with intellectual and physical disabilities

“I like that she rings and checks in with me. Every time she rings I seem to need to talk with her. It’s amazing that it’s gone from something that didn’t exist before to this. I really don’t know how I got by without it.”

Mother of 17 year old child with intellectual disability

“I forget lots of things but my FSC knows where I am at. She rings and asks how I went with this or that. She knows where I am at more than I do. She keeps track of what’s happening.”

Grandmother of 8 year old child with autism and intellectual disability

On advocacy

“The best thing has been that they have gone into bat for me when I decided to do this course and needed more respite than was available.”

Mother of 17 year old child with intellectual disability

“When we have trouble with the school, she organises meetings and suggests people who should come along. Sometimes I go off on the wrong tram and she’s very good at bringing it back. When you’ve run out of puff you don’t think so clearly.”

Mother of 15 year old with intellectual disability and autism

“I’ve had problems with Centrelink. They say I don’t do enough extra for my son and shouldn’t be entitled to the Disability Allowance. It drives me nuts. That’s where MacKillop

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can be my advocate. I know that I can speak for myself but sometimes it wears me out and I lose confidence in myself.”

Mother of 8 year old child with epilepsy and intellectual disability

On referral to other services

“My FSC arranged for me to have counselling and that’s been good. I didn’t realise there were people out there who could help me. I used to just sit at home and put up with suffering.”

Mother of 17 year old child with intellectual disability and autism

“It’s been hard for me to take breaks from my son, to cut the apron strings. My FSC has encouraged me to link up with a recreational program in our area.”

Mother of 8 year old child with epilepsy and intellectual disability

“We went through a difficult period with our son a few years ago when he was destructive. He would throw things. In fact MacKillop replaced the dining setting he broke. Our FSC referred us to the BIST team and a person came out who gave us strategies for managing. When you are so emotionally involved you don’t see what’s happening.”

Mother of 11 and 7 year old children with autism and intellectual disability

4.7 Flexible Support Packages are innovative

As demonstrated in 4.4 above, families emphasised the value of individual innovative solutions to needs they expressed and their appreciation of the program initiatives developed with the Making a Difference and Early Choices Programs. These initiatives included:

- respite for the child with a disability
- respite for other family members
- opportunities for skill development and increasing personal awareness
- opportunities for socialising and building social networks
- opportunities for promoting community inclusion
- opportunities for recreation, having fun and relaxation.

Quotes:

“MacKillop invited me to a pampering weekend at Daylesford. They said they pulled the names out of a hat. It was a wonderful break.”

Mother of 17 year old child with intellectual disability and autism

“I used to go to the get togethers for parents with the older parents. It was interesting to hear what they’ve been through. They’ve done it tougher than us without the helping hands we’ve got. Their children are now in their 40s and they’ve survived. It’s important to me to think that there is a future out there for my son.”

Mother of 15 year old child with intellectual disability and autism

“We have three children and two of them have disabilities. My son has been to some of the siblings activities. They have helped him to realise he’s not the only one in the world in this situation. It’s hard for him when kids come over and won’t come back again.”

Mother of 15 year old child with Down syndrome

“Our daughter just went to the camp for siblings and she had a fantastic time. She met three other little girls on the camp who had siblings with disabilities and she got to talk about what

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it’s like in a way that she can’t do at school. Everyone at school knows that she has a sister who’s in a wheelchair but she can’t talk about her to those kids in a way that they would understand. She is a mini carer as well. Apparently they discussed disabilities and what kids feel. She couldn’t come to me and complain about her sister because she knows that I would get upset but she could talk to a third party and let off steam. They are going to do activities during the year as a youth group.”

Mother of 12 year old child with cerebral palsy

“My daughter is in the ‘Famous Eight After School Pick up Club’. It’s fantastic for them. Right from the start they became good friends. She will come home and say, ‘so and so’s brother is absolutely crazy’. It makes her feel good. She’s got lots of friends at school but none of them have a brother or sister with a disability. It’s really important to us.”

Mother of 11 year old child with epilepsy and intellectual disability

“One time they organised an activity day for the kids on their school curriculum day. It was great because I had to go to school that day.”

Mother of 17 year old child with intellectual disability and autism

“This year they had an outing for my son overnight. It was respite for us but also an outing for him. I said to another Mum, I wish it’d been two nights and we both agreed we were greedy! He doesn’t deal well with change so I was really worried what he would be like. They told me he was a thorough gentleman and I was so proud.”

Mother of 15 year old child with autism and intellectual disability

“Our FSC said our son was great on camp. He had manners and helped with the dishes. It was good for us to know that because we don’t see it.”

Father of 18 year old child with autism

“My grandson goes to the youth group at MacKillop every Tuesday during the school term. They pick him up in a minibus at 3 and then he comes home in a share taxi around 6. It’s a really important group for him and its respite for me.”

Grandmother of 15 year old child with cerebral palsy

“Our son went to Jirralingha with MacKillop these holidays and I made sure I took the other two off somewhere. When he’s not with us we try to do something he can’t do. That sort of thing is nice for him because he doesn’t get invited to other people’s places like other kids do. He doesn’t get invited to parties or to play. It makes him feel special.”

Mother of 9 year old child with cerebral palsy

4.8 Perspective of Family Services Coordinators

Family Services Coordinators interviewed during the consultation expressed views similar to those of the families involved. There was a high degree of congruence between the characteristics they identified as core components of Flexible Support Packages and features valued by families. Quotes from FSCs which highlight the congruence include:

“Some families want me to come as often as I can. Families go up and down. Sometimes you work with them a lot for 3 or 4 weeks and then you won’t hear from them for 3 or 4 weeks. It just depends on what’s happening.”

“You can set kids up into recreational programs for a whole year. Sometimes this encourages organisations to take them on. There is one family who wanted their child to

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learn to swim. He has cerebral palsy and was terrified of the water. He finally agreed and two years later he can swim the length of the pool!”

“You are actually following the journey of the family. You are there for the episodes when the grief surfaces again, for the transition times, the starting primary school, moving to secondary school, moving on to the adult world.”

“We really work alongside families without dictating to them. That’s why we call ourselves ‘family services coordinators’ rather than ‘case managers’. We like the idea that we are a key worker and a resource person working alongside families.”

“Families are in charge of driving their own plans. They have an expenditure sheet attached to their own plans and the opportunity to continually revise it. The ‘care plan’ is like a contract between the family and the FSC.”

“Families are fantastic at knowing what’s best for their children.”

“Some families find it helpful to have someone take on research about a certain piece of equipment. It’s a big relief for them because it’s a lot of work.”

“The preventative aspect of this model is probably underestimated. We probably prevent family breakdown and relinquishment of children. The numbers of families who relinquish children are very low.”

“Families say they often find it hard to be heard by schools. Sometimes I go with parents to meetings at the school. I don’t say anything but just having me there helps them to be heard.”

“We try everywhere to find funds to get people what they need. I would never say that I can’t help. We always try really hard.”

“Sometimes therapists request us to fund something they think the families need but families tell us they need something different. I knew a family where the therapist wanted us to purchase a certain piece of play equipment for a child. The family had other priorities, like petrol to attend the hospital for appointments. This child had lots of siblings and played with them all day.”

“Families don’t always know what they want. It’s not easy for them. I wait a long time before I finish a ‘care plan’. I do a draft first but I don’t fill everything in. Families think of things they have forgotten to include. They talk with other parents and come up with ideas. I send it over and over again until I finish it. Taking times seems to be really important.”

“We are always looking for inclusive school holiday programs. We started our own in Melton because we had a group of interested families who were stressing out because they couldn’t access the Council Programs. It’s for three days during January and it includes kids from MacKillop’s Youth and Family programs here.”

“Each year we organise a family day at ‘Adventure Park’. It’s a great day because families can do what normal families do.”

“A creative ‘initiative’ has been to pool the funding for a group of children with a disability from the Carer Respite Centre to run some day activities. The kids have enjoyed being in a group rather than going out alone with a carer. Parents appreciated that we did all the organisation.”

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“There’s a mix of different people on this Team. We can borrow from one another to take back ideas to families.”

“It’s helpful working with a group of families rather than with small numbers of families. We don’t group our 53 families together and do the same thing with them but because we’ve got that number then we have the capacity to think of creative and innovative programs. If we were only working with one family, or if 20 service providers were working with 20 different families, then I’m not sure that capacity would be there.”

“There is a lack of red tape here so that we can get money quickly and easily. If we need money urgently, we can get it the same day whereas other agencies can take weeks to get money for something.”

“One of the big things is that our families are very isolated and can’t always fit in to the community. We try to enable families to fit into the community but sometimes they can’t and then we look at creating services.”

5. QUANTITATIVE DATA

The tables in this section gather together quantitative data on the Making A Difference program including Intensive Support Service packages and Short Term packages and the Early Choices program. Unless otherwise stated the tables combine data from Barwon and Metro programs. The data applies to the January-February period in 2005.

5.1 Making a Difference Intensive Support Packages data

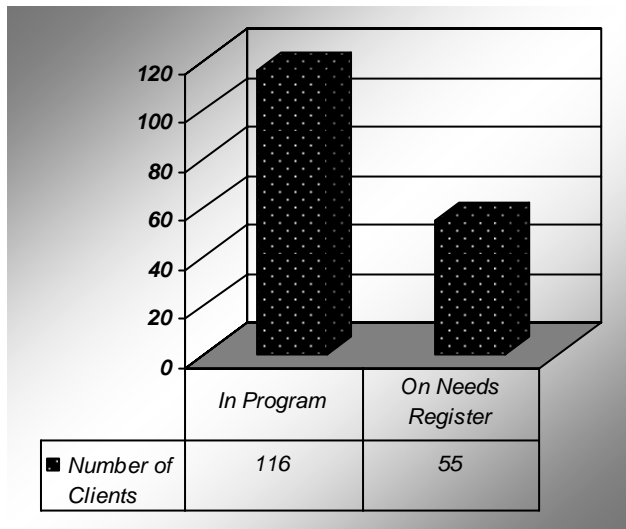


Table 1. Client numbers in Making a Difference Intensive program

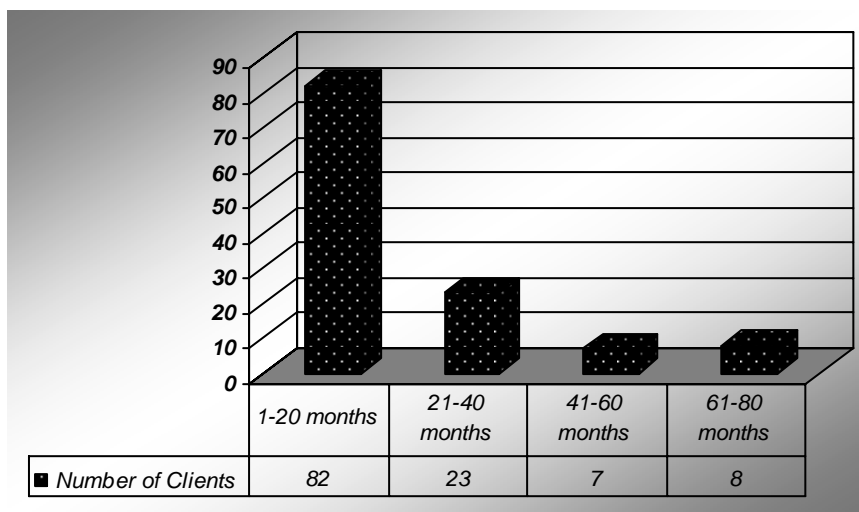


Table 2. Length of time in Making a Difference Intensive program

“I Feel Like I Count”

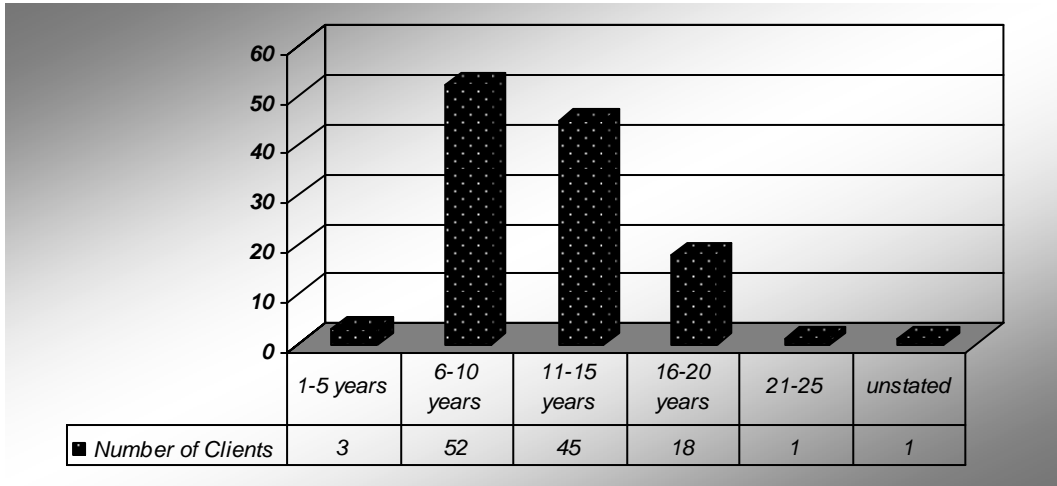


Table 3. Age of clients in Making a Difference Intensive program

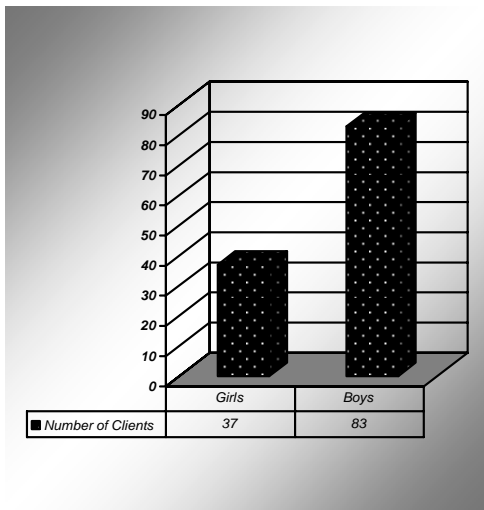


Table 4. Gender of clients in Making a Difference Intensive program

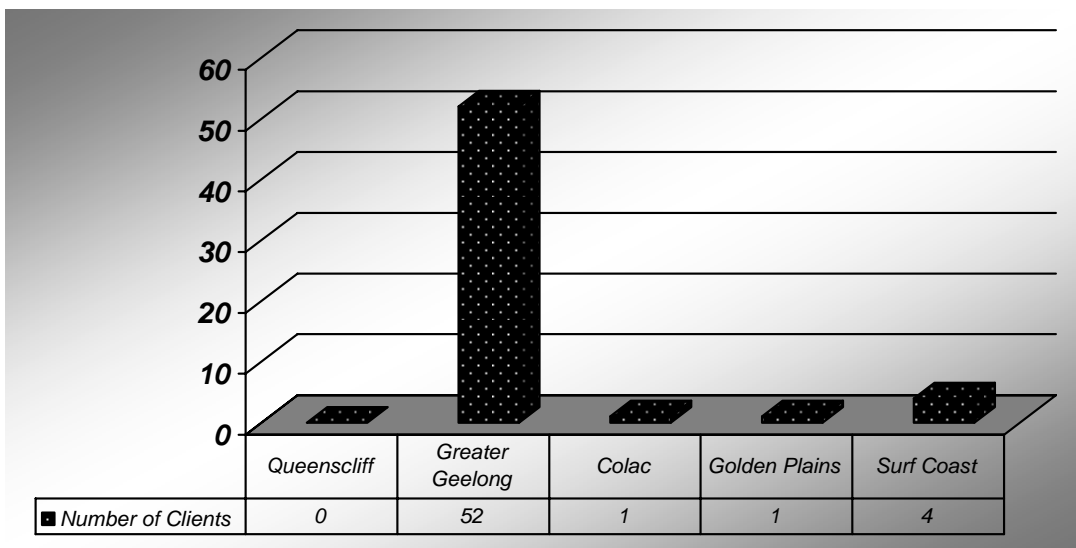


Table 5. Location of clients in Making a Difference Intensive program in Barwon region

“I Feel Like I Count”

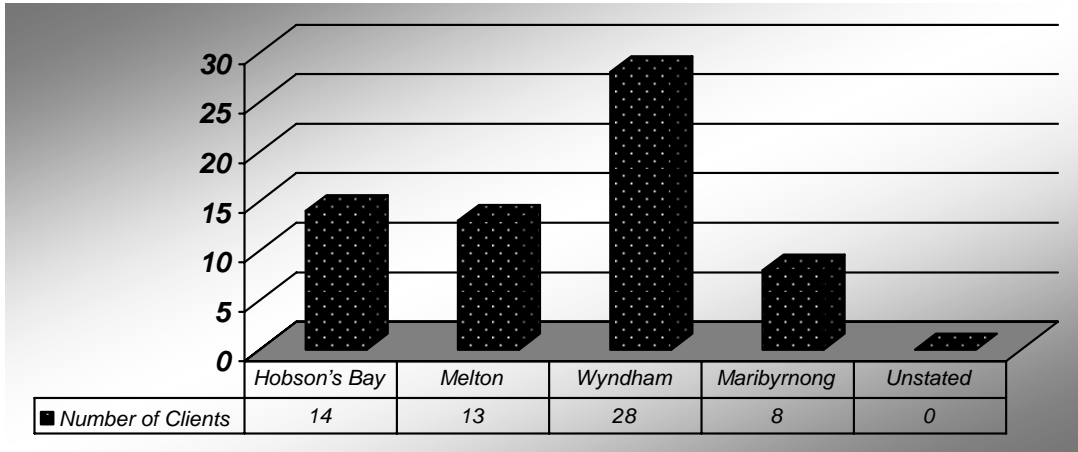


Table 6. Location of clients in Making a Difference Intensive program in Metro region

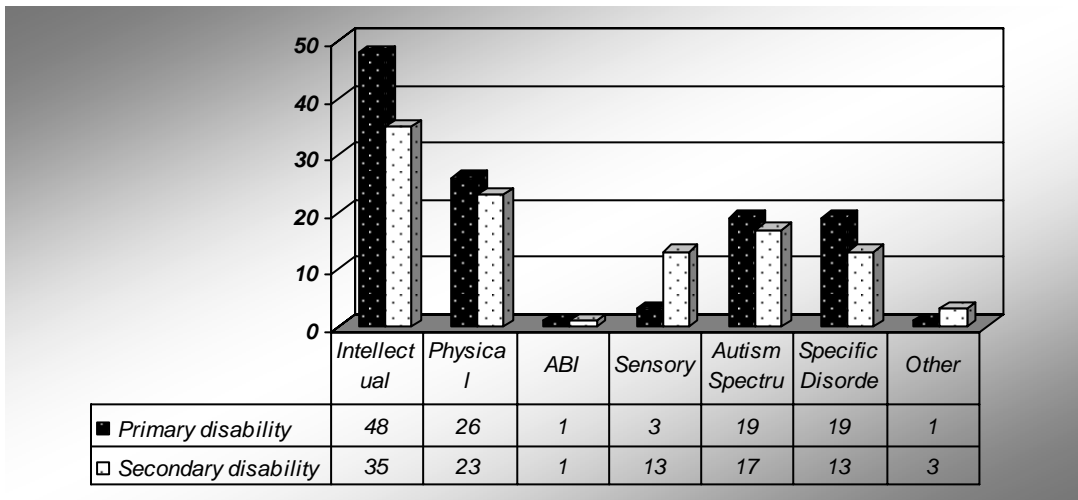


Table 7. Types of Disability of clients in Making a Difference Intensive program

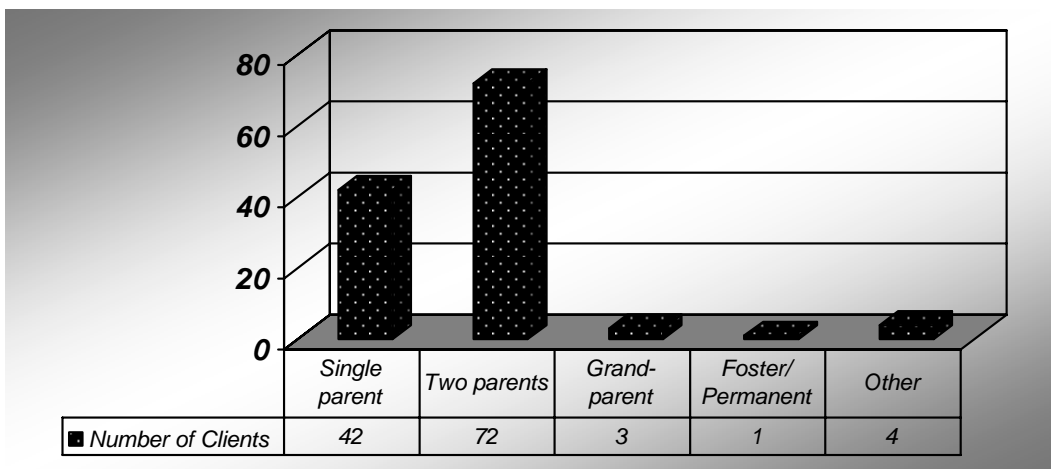


Table 8. Household Types of clients in Making a Difference Intensive program

“I Feel Like I Count”

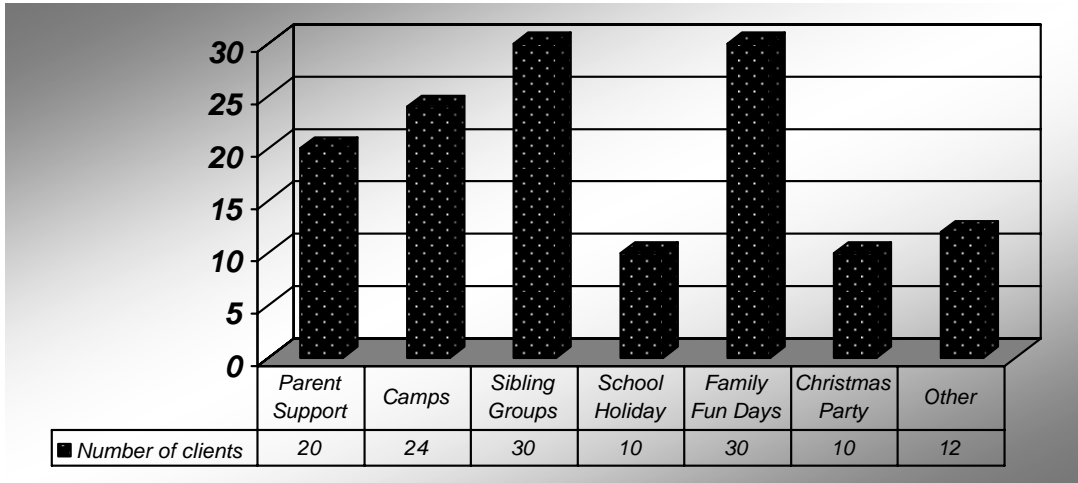


Table 9. Program initiatives in Making a Difference Intensive program

5.2 Making a Difference Short Term Packages data

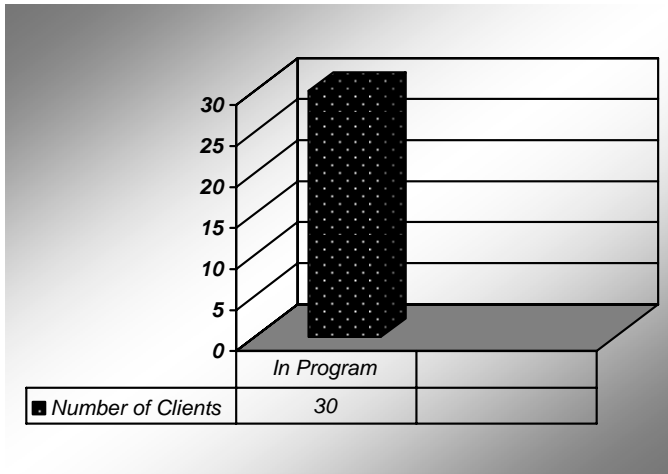


Table 10. Client numbers in Making a Difference Short Term program

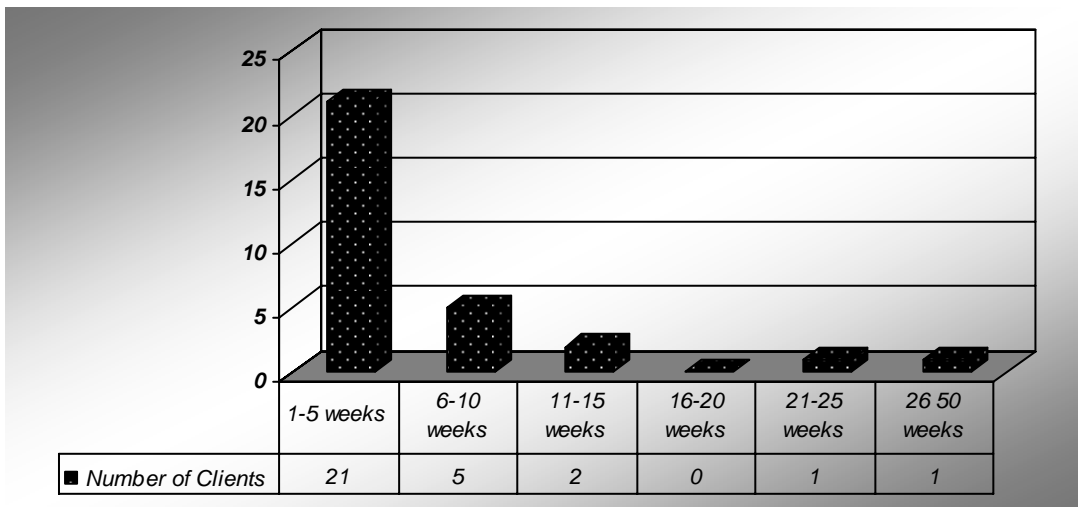


Table 11. Length of time in Making a Difference Short Term program

“I Feel Like I Count”

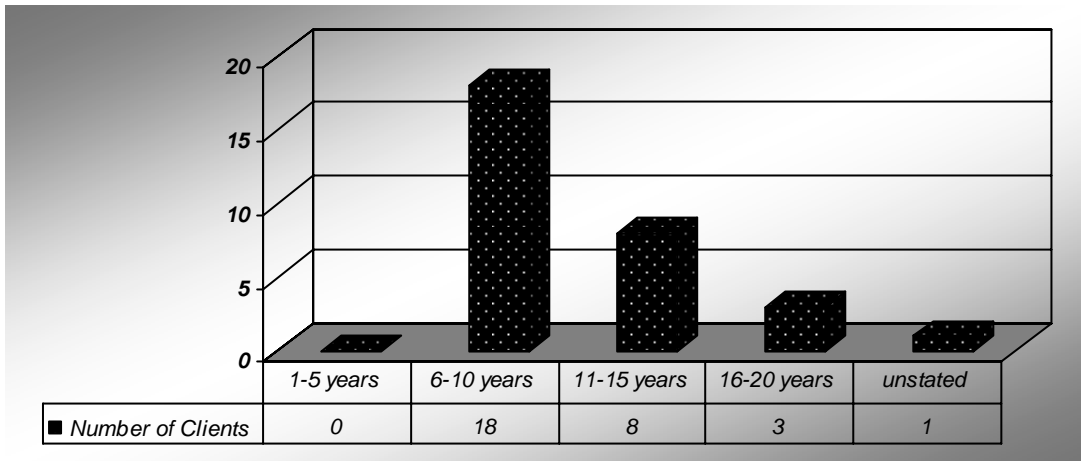


Table 12. Age of clients in Making a Difference Short Term program

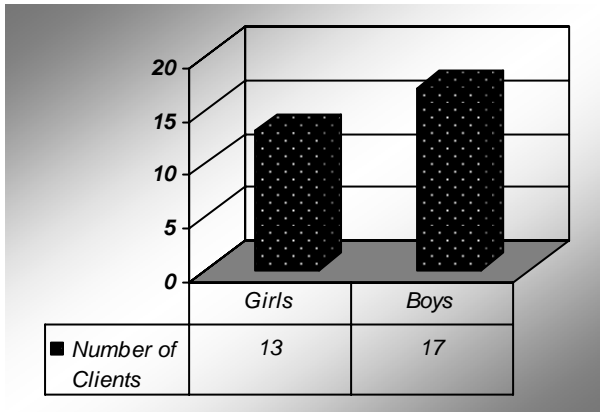


Table 13. Gender of clients in Making a Difference Short Term program

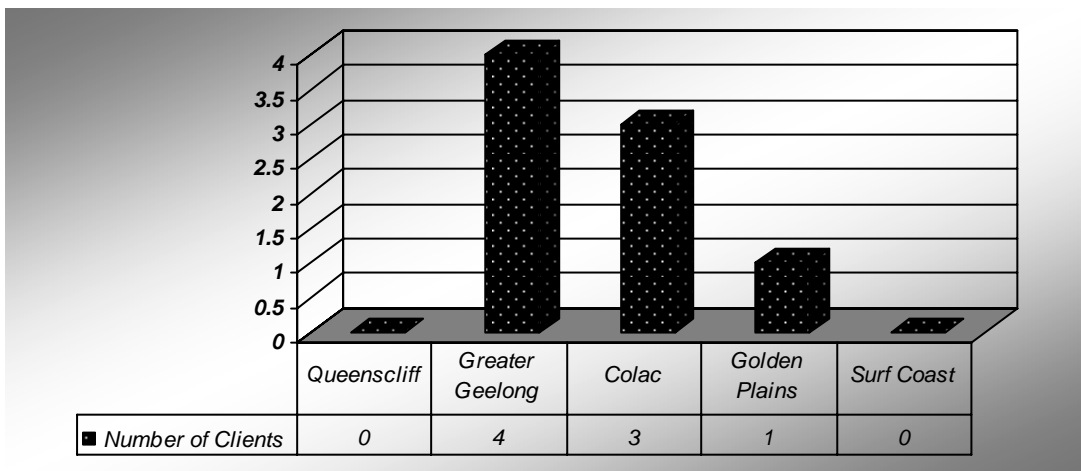


Table 14. Location of clients in Making a Difference Short Term program in Barwon region

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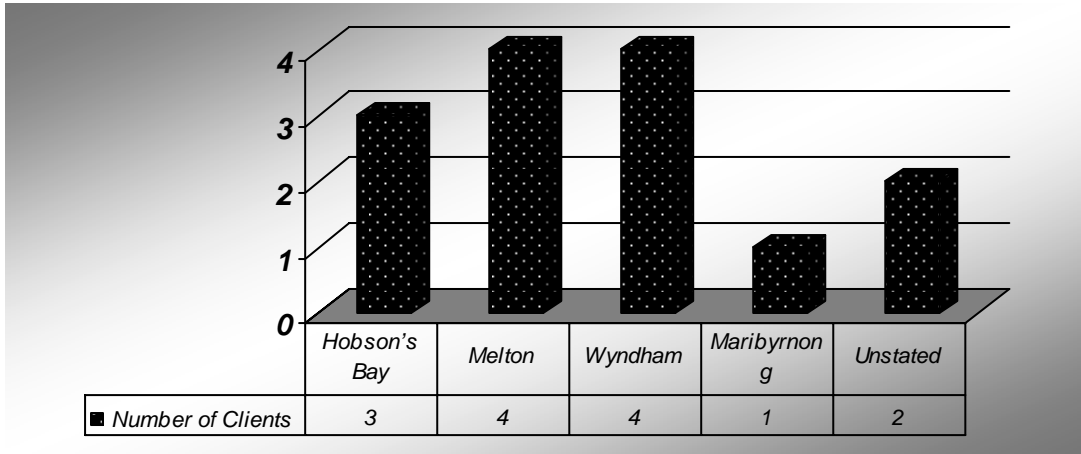


Table 15. Location of clients in Making a Difference Short Term program in Metro region

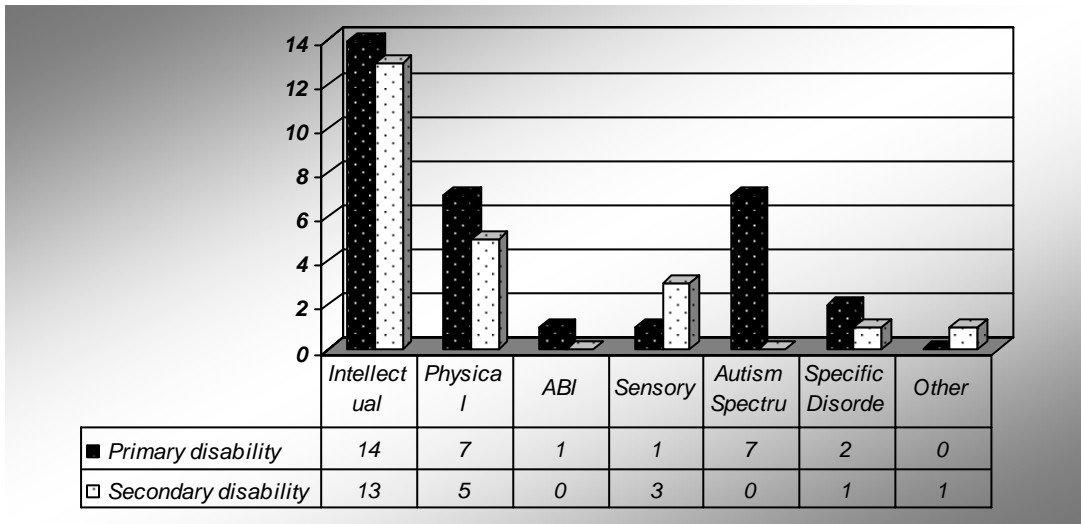


Table 16. Types of Disability in Making a Difference Short Term program

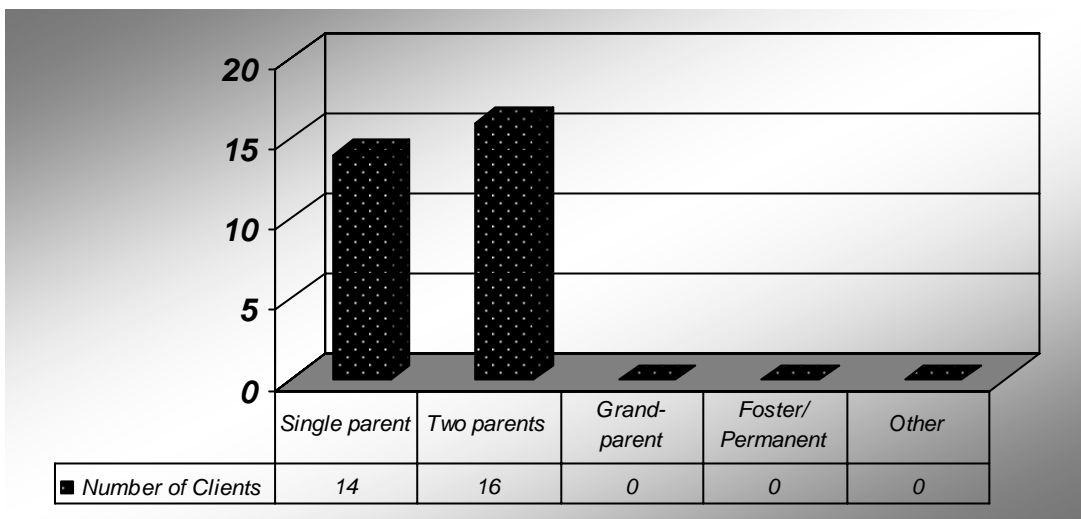


Table 17. Household Types in Making a Difference Short Term program

“I Feel Like I Count”

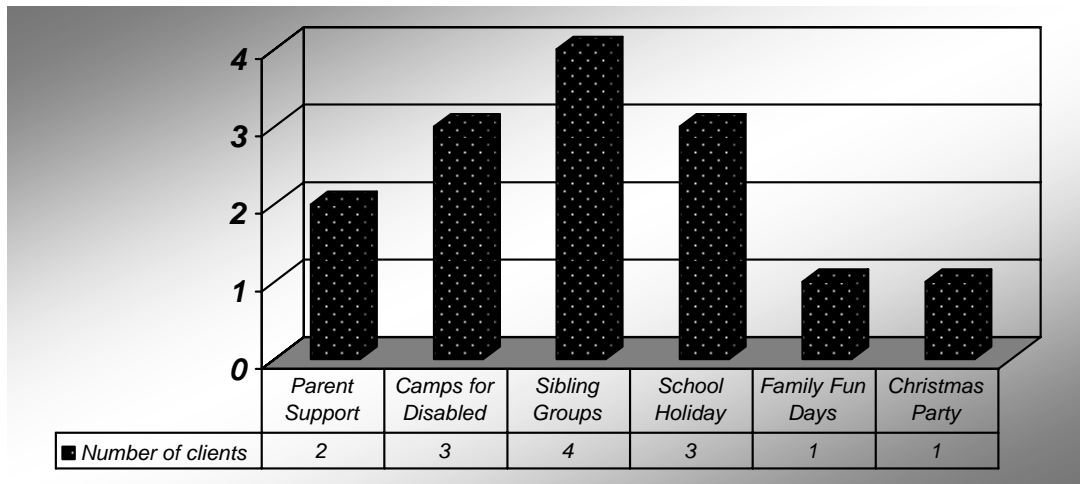


Table 18. Program initiatives in Making a Difference Short Term program

5.3 Early Choices Program data

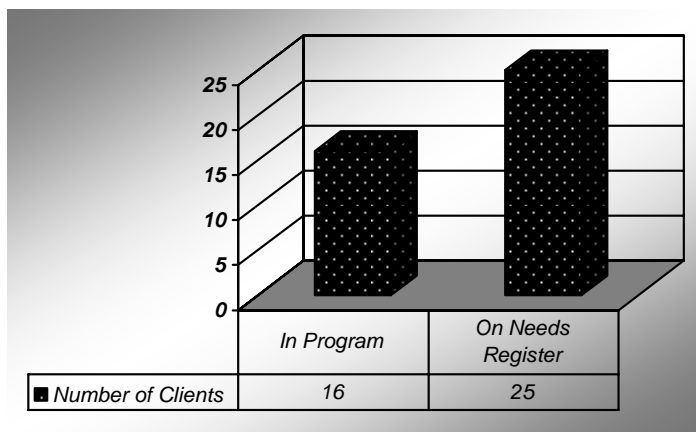


Table 19. Client numbers in Early Choices program and on Needs Register (Metro region)

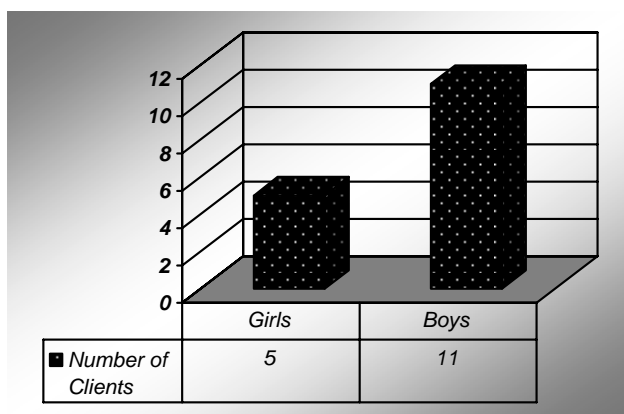


Table 20. Gender of clients in Early Choices program

“I Feel Like I Count”

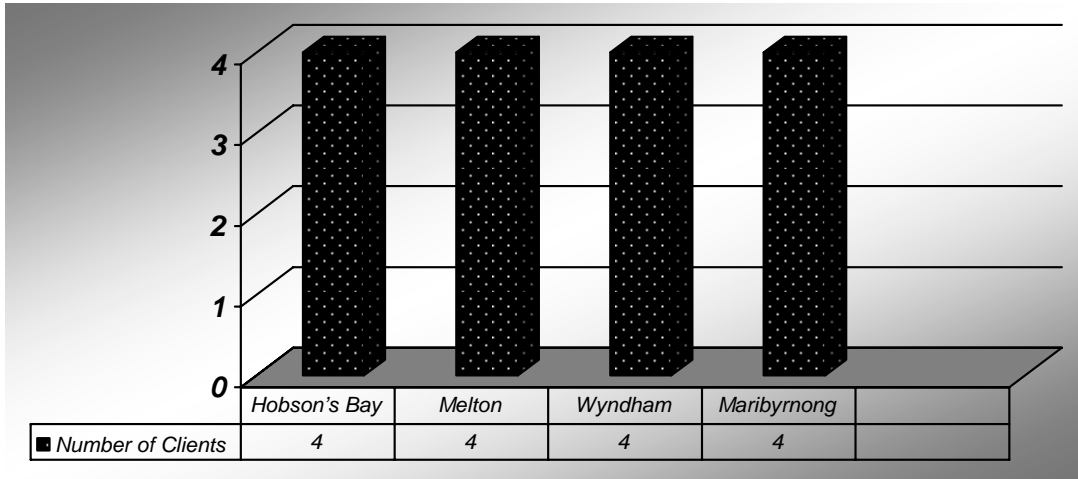


Table 21. Location of clients in Early Choices program in Melbourne’s Metro region

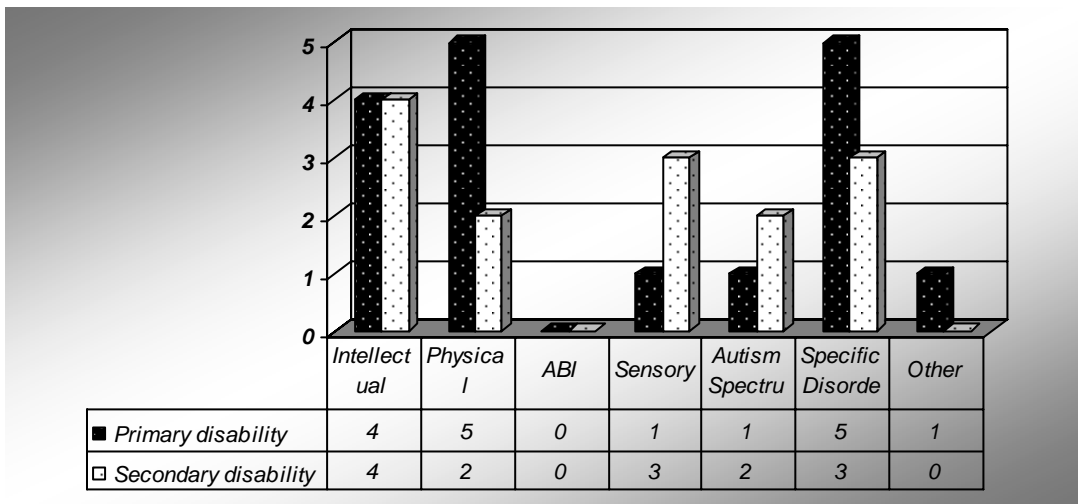


Table 22. Types of Disability in Early Choices program

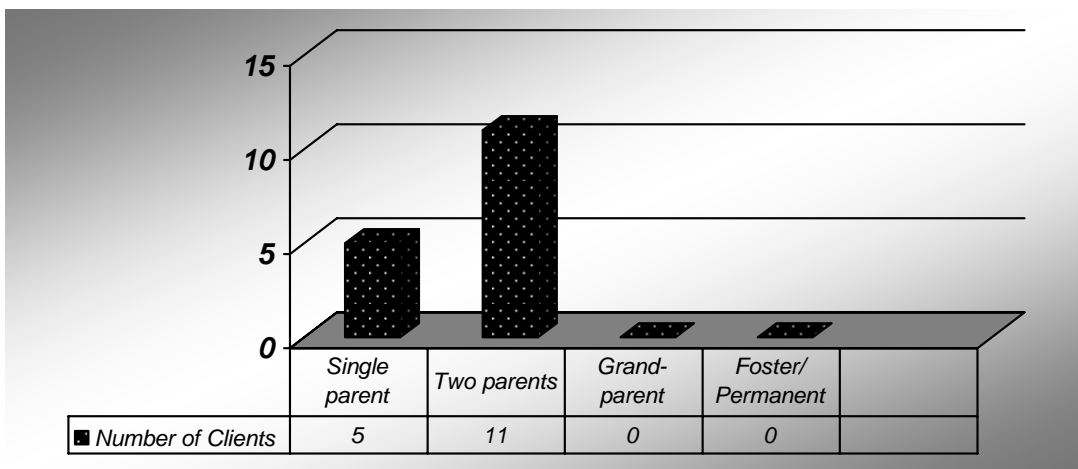


Table 23. Household Types in Early Choices program

5.4 Conclusion

Other data was gathered which is not tabulated here (see Appendix F for the data collection sets). The cultural background of families engaged in these three programs was very broad, including Chinese, Croatian, Egyptian, Filipino, Greek, Indian, Italian, Lebanese, Macedonian, Maltese, Slovenian, Spanish, Sri Lankan, Turkish, Vietnamese, and Yugoslav backgrounds. Household income types were distributed more or less equally across employment and pension sources, and homes were owned or rented in roughly equal proportions. The amounts of discretionary funding provided to each family cover a broad spectrum.

The quantitative data thus demonstrates the broad range of families, disabilities, age groups, and initiatives involved in the delivery of Flexible Support Packages, further indicating the flexibility of these service models.

6. DISCUSSION

6.1 Individualised Planning and Support: Combining Planning and Service Provision

In the context of the new policy focus on individual planning and support, it is relevant that individualised planning and support is a central feature of the Making a Difference and Early Choices programs. The person with the disability and their family direct the development and implementation of their “individual service plan” (Wagstaff, 2004, 51). The planning is “person centred” in that it considers aspirations and capacities expressed by the service user, or those speaking on their behalf, rather than their needs and deficiencies (cf. Owen et al, 2002, 150).

In the Making a Difference and Early Choices programs, the one provider arranges planning facilitation, planning review and funding. Families and practitioners believe this enhances the programs’ flexibility and responsiveness. Family Services Coordinators (FSCs) are able to respond quickly to needs as they arise without needing to seek approval from a third party. The “care and expenditure plan” can be adjusted or reviewed at any time simply by contacting the FSC. For many families with a child with a disability, life is unpredictable and it is difficult to foresee needs and wants 12 months ahead. In addition it is a strong feature of these programs that planning is an ongoing process between families and their FSCs rather than a once off procedure. In these programs, planning is undertaken by the FSC who is also responsible for provision of the service.

Combining planning and service provision ensures that goals set by the family are realistic and achievable and that communication is enhanced, duplication is avoided, and administrative costs are minimised. Additionally, problems are avoided by reducing the number of people involved with the one family.

Providing people with the support required to achieve their goals, rather than limiting goals to what services typically can manage, is seen as a key objective of person centred planning (Owen et al, 2002, 150). A particular issue that should be addressed in the redevelopment of disability services, and related to individualised planning and support, is the “recognition that a commitment to family based care carries with it a commitment to comprehensive, proactive family support to enhance parental functioning, reduce stress and enhance quality of life for family members, prevent placement and foster optimal skills in all areas of functioning in a child with a disability” (Wagstaff, 2004, 33). The findings of this consultation support Wagstaff’s claim. Families emphasised the benefits of the assistance they received through emotional support, the coordination of services, and the flexible, responsible, individualised, resourceful, family centred services provided by a case manager, the Family Services Coordinator.

“Regular, consistent respite care in-home and out-of-home is an essential aspect of the disability supports required to enhance family functioning” (Wagstaff, 2004, 47). In Making a Difference and Early Choices, “program initiatives” offer additional support to families. “Program initiatives” can be seen on the respite continuum as described by Wagstaff as extending the respite care opportunities of the family and the child with a disability as well as providing opportunities for education, mutual support and enjoyment (Wagstaff, 2004, 50 and this report, section 4.7 above).

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The new individualised planning and support approaches being developed by government are characterised by an emphasis on tailoring services to suit individuals and families, by being present and future focussed, by allowing people choice in decisions affecting their lives, and by respecting that families know what they need and want. These characteristics were all endorsed by families and practitioners as vital key features of the Making a Difference and Early Choices programs. In fact they are important components of the seven key features of Flexible Support Packages provided by the Making a Difference and Early Choices Programs identified in this consultation. These key features are crucial, core elements of any individualised planning and support model directed towards families with children with disabilities.

6.2 Conclusion and Recommendation

Given such strong affirmation shown by families for Making a Difference and Early Choices programs, such services should not be lightly abandoned. If the Flexible Support Packages model is so highly valued, why are significant resources being allocated to the development of new models of service delivery? What will be the impact of new models of service on the Flexible Support Packages? Why were the Making a Difference and Early Choices Programs not evaluated in order to inform the development of individualised support and planning models, in particular the Support and Choice Initiative? These questions should be considered with great attention by supporters of individualised support and planning and best practice in the provision of services to families with children with disabilities.

We therefore recommend that a comprehensive evaluation of Flexible Support Packages programs, in particular Making a Difference and Early Choices, be undertaken by DHS. Important elements of the evaluation would be to consider the programs in terms of them being models of individualised planning and support, their cost effectiveness, and the role of case management.

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**Appendix A
Letter to families inviting participation**

Tuesday December 7 2004

Dear Families

I am writing to invite you to participate in an important research project we are undertaking this Summer.

The aim of the project is to review the Making a Difference and Early Choices Programs provided by MacKillop Family Services to children with a disability and their families. In this Review we want to learn from families about the services they receive. We want to understand what services mean to families and how services make a difference to the lives of family members.

Our aim is to present the findings of the Review at an important disability conference in mid 2005 and to prepare a paper to be published in a journal.

We have appointed an experienced social worker, Nerida Mulvey, to undertake the Review. Your conversation with Nerida will be confidential and no identifying information will be published.

Nerida would like to arrange a time to talk with you in a group over coffee at MacKillop Family Services, talk with you in your own home or talk with you over the telephone. She expects that the interview will take around one to one and a half hours. She would like to talk with you during December or January and is happy to come out in the evening or on the weekend. She can arrange child care if that helps.

I understand how difficult it is to squeeze another thing into your lives at this time of year and I apologise for adding to your busyness. As a gift to thank you for participating in this Review we would like to give you two tickets to the movies for you to enjoy during Summer!

If you are able to become involved or would like more information about the Review please return the enclosed form in the envelope provided. Nerida will call you back to respond to your questions and/or make a suitable arrangement.

Warm wishes

Karyn Hobday/Kathryn Barry
Manager, Bayview Disability Services/ St Anthony's Disability Services
MacKillop Family Services

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**Appendix B
Plain Language Statement**

Review of Flexible Support Packages (Making a Difference and Early Choices Programs) provided by MacKillop Family Services, Barwon and Western regions

Plain Language Statement

This is a statement in plain English to inform you about a study being undertaken by MacKillop Family Services. This study has the approval of the MacKillop Family Services Ethics Committee.

This study was initiated by the Managers of the Disability Services in MacKillop Family Services.

Over the years, several evaluations of Flexible Support Packages have been undertaken by consultants and government departments. Primarily these evaluations have focused on the delivery of programs from the perspective of service providers. In this Review I want to learn from families about the services they receive through these programs. I want to understand what services mean to families and how services make a difference to the lives of family members.

MacKillop Family Services wants to know what families think about the services they receive from them because they want to tell the government and other service providers about the value of their work. Although the Government provides funding for these services, it doesn't always know the details of the work.

I am particularly interested in hearing about innovative and creative solutions that families and their Family Services Coordinators have found to problems they have experienced. MacKillop Family Services believes these should be commonplace and available to all children with a disability and their families.

I am seeking your informed consent to be interviewed.

Participation is voluntary and participants will be asked to sign a consent form prior to being interviewed. Each interview is expected to last between one and one and a half hours. With your consent the interview will be tape recorded. No information of a personal or confidential nature will be collected. Participants can withdraw at any time. Comments made during discussions may be included in the written report, but the source of comments will not be named.

All information collected will be securely stored by me in a locked filing cabinet during the Review and passed to MacKillop Family Services for secure storage on completion of the Review.

The aim is to present the findings of the Review at an important disability conference in mid 2005 and to prepare a paper to be published in a journal.

Nerida Mulvey
B.A., Dip. Soc.Studs.; Dip.Fam.Ther.; MSW.

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Appendix C Questions for families

Questions about your child

- Can you tell me about your child?

Questions about your family

- Can you tell me about you and the other people who live in your household?

Questions about your links with other agencies and services

- Do you receive services from other specialist agencies? What services do you receive? How does MacKillop compare with these services?
- Are you linked with local, mainstream services? Did your FSC assist you in making these links?

Questions about the support you received from MaD and Early Choices

- Can you remember when you first became involved with the program? Can you remember the reason you became involved?
- Can you tell me what services you have received from the program?
Prompts:
Funds –
 Were funds used to buy anything for you?
 To employ anyone to help you or your child?
 To pay fees for services you were using or wanted to use but couldn't afford
 And/or
Case management support –
 Did the FSC advocate for you with any government department or other service on your behalf?
 Did the FSC assist with coordination of services?
 Did the FSC organise for you to receive any service/benefit you weren't already receiving?

Questions about your involvement in any of the ‘program initiatives’ facilitated by MacKillop Family Services?

These include:

- The After School Club (in partnership with Geelong Employability)
- Parent Support Group (in partnership with Karingal)
- Sibling Groups/camps
- School holiday activities
- Occasional activities such as;
 - Pampering Mornings
 - Fishing Trips
 - Music Workshop
 - Family Fun Days
 - Fun Arts in the Neighbourhood
 - Residential Camps
 - small scale get togethers eg neighbourhood morning teas
 - one off education sessions for parents

Do you have any comments on these?

Questions about the impact of the support you have received

- What has been the most important/helpful assistance you have received? Why?

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- How has being a part of the program ‘made a difference’ to your child’s life?
- How has being part of the program made any significant difference to your life, your partner’s and your other children’s lives?
Prompts:
Are pressures/stress on you or your family reduced?
Do you feel more or less able to cope with caring for child?
Have you gained more information about services and assistance to which you are entitled?
Do you feel more confident about approaching services?
- Is there assistance or support you consider your family needs which you have not been able to receive?
- Are there things you don’t like about the program?

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**Appendix D
Consent form**

**Consent Form for Review of MacKillop Family Services Flexible Support Packages
(Making a Difference and Early Choices)**

I have received a statement explaining the interview involved in this Review and the content of this consent form has been explained to me.

I consent to participate in the Review of Making a Difference and Early Choices to be undertaken by Nerida Mulvey.

I have been informed that I am free to withdraw from the Review at any time.

The privacy of the information I provide will be safeguarded.

The security of the research data is assured during and after completion of the Review.

The data collected during the Review may be presented at a Conference and may be published. No identifying information will be used.

Participant’s consent:

Any complaints about your participation in this project may be directed to;
Karyn Hobday, Manager, Bayview Disability Services, MacKillop Family Services. PO Box 858, North Geelong 3215

Or

Kathryn Barry, Manager, Disability Services, MacKillop Family Services, 118 Commercial Road, Footscray

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Appendix E Questions for workers

1st interview

Questions about you

How long have you worked at MacKillop?

How long have you worked in the disability field?

What are your professional qualifications?

Questions about Making a Difference and Early Choices

What do you think are the strengths of the programs?

What do you think are the weaknesses?

Questions about fundamental principles of the programs

- ***“Emphasis in our program is on being flexible”***

How flexible do you think the program is?

Is it possible to change the care and expenditure plan when an unexpected need arises?

Can you think of examples of problems for which creative solutions were found to problems by you and the FSC?

- ***“Emphasis in our program is on quick decision making and responsiveness”***

How responsive have you found the program?

How often do you have contact with your families?

Who usually initiates the contact?

- ***“Services will be tailored to the needs of families”***

Were the services you provided tailored to the specific needs of the families?

Were families involved in the development and ongoing review of your care plan?

- ***“Making a Difference Program and Early Choices are family centred programs”
Brochure***

In your experience does the program consider the needs of families as well as children with disabilities?

Can you think of any examples?

- ***“Every person who is approved for support is allocated a case manager and he/she will have ongoing contact with you” Information pack***

How important is your relationship with the family? Why?

Can you think of any examples?

- ***“Information on available and relevant services is provided to enable families to make informed choices” Principles underpinning practice***

Are families offered a variety of choices?

- ***“We aim to ensure that families are empowered to maintain their roles as effective guardians for their child/children with disability”***

Do you feel families have had enough say in decisions about the assistance they receive?

Did you feel families have control over the planning and allocation of discretionary funds?

- ***“Long term support”***

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How important is it that the packages be offered on a long term basis?

- Are there any ways in which the approach taken by the FSC can be improved?

Questions about involvement in any of the ‘program initiatives’ facilitated by MacKillop Family Services?

- The After School Arts Club
- Parent Support Group
- Sibling Groups/camps
- School holiday activities
- Occasional activities such as;
 - Pampering Mornings
 - Fishing Trips
 - Music Workshop
 - Family Fun Days
 - Fun Arts in the Neighbourhood
 - Residential Camps
 - small scale get togethers eg neighbourhood morning teas

Do you have any comments on these?

Are these activities filling gaps not available in the generic service system?

Questions to ask families

Do you have any suggestions about how to talk with families about their experiences of the Making a Difference and Early Choices Programs?

2nd interview

Questions about particular children

- Age
- Gender
- Nature of disability (CSDA minimum data set)
- Multiple disabilities
- Specific care needs (requirements for assistance with activities of daily living, continence, health, behavioural difficulties, abilities in communication and understanding, night time care needs, combinations of characteristics requiring significant levels and/or special types of care)

Questions about particular families

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**Appendix F
Data collection form**

MacKillop Family Services Review of Flexible Support Packages

‘Snapshot’ of families and children receiving Flexible Support Packages

Today’s date: __ / __ / __

Program Information:

Please select the program relevant to you (tick the box/es):

Families currently receiving a package

Making a Difference Program (Short Term)

Making a Difference Program (Intensive)

Early Choices

Early Choices (one off)

Making a Difference Program Needs Register;

Is the family also currently receiving a STAP?

Has the family received a STAP in the past?

If so, how many? What years? _____

Is the family waiting for a long term package?

Is the family waiting for a STAP?

Early Choices Program Needs Register;

Has the family received a one off payment?

If so, how many? What years? _____

Is the family waiting for a long term package?

Is the family waiting for a one off payment?

Name of current case manager? _____

On what date did this package commence? __ / __ / __

How long has current case manager
been involved (months)? _____

How many case managers has the family had? _____

Child with disability’s details

Child’s name: _____

Age of child: _____

Child’s gender (please circle): Male / Female

Please select your local government area (tick the box):

Borough of Queenscliff

City of Greater Geelong

Colac

Golden Plains

Hobson’s Bay

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Melton
Surf Coast
Wyndham

Nature of primary disability (tick the box)

Intellectual	<input type="checkbox"/>	sensory	<input type="checkbox"/>
Physical	<input type="checkbox"/>	autism spectrum	<input type="checkbox"/>
ABI	<input type="checkbox"/>	specific disorder	<input type="checkbox"/>
Chronic illness	<input type="checkbox"/>	degenerative neurological condition	<input type="checkbox"/>
Other _____			

Nature of secondary disability (tick the box)

Intellectual	<input type="checkbox"/>	sensory	<input type="checkbox"/>
Physical	<input type="checkbox"/>	autism spectrum	<input type="checkbox"/>
ABI	<input type="checkbox"/>	specific disorder	<input type="checkbox"/>
Chronic illness	<input type="checkbox"/>	other _____	

Family caring for child

Please select household type (tick the box):

Single parent
Two parents
Grandparent
Foster / permanent care families
Other (specify) _____

What is the ethnic background of the family?

Does the family require an interpreter (please circle)? Yes / No

What is the main source of income in the household (tick the box)?

Pension / benefit
Single full time wage
Combination of full and part time wages

Please select current housing situation (tick the box):

Purchasing / ownership
Public / private rental
Living with relatives

Who lives in the household (tick the box)?

Siblings
Grandparents
Other (specify)

Please give details of the siblings living in the household:

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Age: _____ Gender (M / F) _____
Sibling One: _____
Sibling Two _____
Sibling Three _____

Who is the child with the disability’s primary care giver in the household (tick the box)?

Mother
Father
Grandparent
Other (specify)

List any significant others living in the household not listed thus far:

Use of package;

How have brokerage funds been used?
Please estimate % for last year

Respite
Material assistance
Equipment (includes continence products)
Transport
Other (specify)

Has the family used case management? Yes / No

Participation in ‘program initiatives’:

Please tick the box of any programs the family has been involved with:

The After School Club (Bayview)
Parent Support Group (Geelong, Melton)
Residential camps for children with disabilities
Sibling groups / camps
School holiday activities (Melton)
Family fun days
Activities for mothers – pampering mornings
Activities for fathers – fishing trips
Fun arts in the neighbourhood (Geelong)
Christmas get together
Small scale get togethers (eg. Morning teas)
Other (specify)

Do you have any comments about these?

Thank You for completing this questionnaire!

Please return completed questionnaires to Kathleen or Karyn for collection by Nerida Mulvey at her earliest convenience.

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