

## Area of focus

# Supporting families raising a child with a disability

### Why do we have this focus?

There are approximately 35,000 children and young people in Victoria with a moderate to severe disability. Parents and siblings of the child with a disability often experience considerable stress responding to the additional needs of the child at the same time endeavouring to try to maintain relationships and respond to other stresses often experienced within families.

### How we address this identified need

**MacKillop Disability Services (Metro)** and **Bayview Disability Services (Barwon)** provide a range of services to assist families caring for children and young people with moderate to severe disabilities by being responsive, flexible, innovative and family centred.

Every family and individual we have the privilege to be involved with is unique. All team members strive to ensure that their work is person-centred, creative and innovative. Families and individuals set goals and objectives within a care plan which provides the framework for our involvement with them.

We work closely with the Department of Human Services (DHS), local government, community service organizations and schools to ensure that families are able to receive the supports they require and request. In addition we consider it important and vital to play a part in developing communities that are responsive to the needs of families with children with disabilities.

Services operate from a family-centred approach building upon strengths within the family and involving the community wherever possible.

Families we worked with this year had access to one or more of the following services:

- Flexible support packages and individual support packages offering short term and intensive case management both through MacKillop and other support services which we call upon for assistance.
- Contracted case management for families with children with complex medical conditions through the Royal Children's Hospital. This enables children that are chronically ill to live at home rather than be confined to hospital.
- Respite and recreation services including, 'Parent to Parent'



#### **Peter\* - Anger Management**

*Peter started a picture and mucked it up, so he decided to paint some flowers instead. Peter likes sport, especially football. Go Collingwood. He has two carers and they are both nice.*

## Notable achievements this year

Some of our notable achievements this year were:

- Growth of the inclusive school holiday activities in Melton. There are 70 families from the Melton Shire receiving services.
- Participation by the *Youth Group* of **Bayview Disability Services** in MacKillop's Art Exhibition in 2005 and the graduation of eight members, many who had been part of the group for six years. In 2006 new participants have been able to experience the fun of the weekly after school youth group held at **St Augustine's Education and Training**. These members all displayed art in MacKillop's Soul Art Exhibition, 2006.
- Ongoing working relationship with Kids Under Cover. Seven families benefit from having a bungalow to lessen stress and maintain the family unit.
- The commencement of the Outer West Sibling Activity Group funded through Carer Links West.
- Parent to Parent successfully supported workshops run for parents on transition, puberty and social stories for parents that have a child with autism. Resource Information for parents that have a child or an adult with a disability was also translated into Vietnamese.
- **Bayview Disability Services'** first family camp, over 2 nights in May, with a pirate theme held at Anglesea and attended by 6 families. Feedback from families was very positive, they enjoyed being able to all be together as a family and also to have the opportunity to have some time to do their own thing and participate in whatever way they liked.



### **Bladen\* - Self portrait**

*Bladen has an intellectual disability. He has painted a picture of himself painting. He loves to ride his bike.*

weekends, pampering sessions for mums and a day out for dads at Calder Raceway, a family camp, school holiday activities, weekly youth group, and camps for young people and children with disabilities. Respite services are also provided by volunteer caregivers in their family home.

- The provision of telephone information and quarterly newsletters to families to make it easier for them to work their way through what can seem to be a maze of services.
- Teaching young adults with a disability independent living skills. **Disability Services (Metro)** provides a residential unit in Melbourne where young adults can live while also maintaining contact with their families. During their time at the residential unit they participate in community activities, learn to handle money, purchase food and other goods, and to cook meals. They also learn to work and live together.
- The development of a plan which assists families and individuals in planning for the long term needs and aspirations of the person with a disability, and in obtaining the necessary services and supports. The plan goes to the Department of Human Services which then organises its implementation.

Many of our services are delivered through our volunteer caregivers to whom we are deeply indebted. Our caregivers provide innumerable ongoing hours of care in their own homes in a professional, committed and enthusiastic manner and we are very thankful and appreciative of the special contribution they make to the lives of the children in their care.

They also assist families to stay connected and supported in the broader community. They transport families to doctor's appointments, meetings, shopping and social gatherings, and help the family to once again feel part of the broader community.

- Parent to Parent West together with Parent Support Program Northern was successful in securing funding to develop a handbook for volunteer parent support groups facilitators.
- As a result of demand and positive feedback our annual Family Fun Day was held for the fifth time at Adventure Park Wallington supported by Highton Rotary. Over 80 family members attended along with Bayview staff and all had a great time.
- We established a new sibling group for boys and held another camp for boys at MacKillop's *Queenscliff Holiday House*. A day at Calder Raceway for Dads has also been held, initiated and supported by our wonderful male volunteers.
- Team members at Bayview have conducted two group courses of six sessions in Signposts, a parent education program for parents of children with intellectual disabilities. The Program Manager has been a member of the Regional Reference Group for this initiative.
- The launch of "I Feel Like I Count", the report of the consultation with families on the *Making a Difference* program in both Geelong and Metro, by two parents who gave very moving accounts of life with a child with a disability at MacKillop's Annual Public Meeting last year.
- As a result of the Bayview Program Manager's study tour visiting organizations in the U.K. several initiatives have occurred, they being:
  - > All team members have received training in person-centred thinking, ie a range of different skills team members can use supporting families and individuals to receive the supports they identify.
  - > DHS (Barwon/South West) has given Bayview a grant to conduct

a training program designed to develop leadership skills and empower parents of children with disabilities in the area of advocacy and making a contribution to the community in which they live.

- A community inclusion and integrated practice model continues to develop at our Melton office. This was a MacKillop initiative that began two years ago. The model brings disability case managers and family support case managers together to develop holistic care plans for families. Integrated practice opens extra opportunities to families that have a child with a disability by entry into a service sector broader than the disability sector of the service spectrum. This practice model represents a collaborative approach to addressing the needs of families and allows for an increase sharing of practice skills and knowledge across programs to the benefit of families.

An example of how this works is the development of Inclusive School Holiday Activities within the Melton Shire to enable children with disabilities to be involved in mainstream recreation. A consequence of this activity has been the joining with Sunshine

Heights Primary School to open up new friendships and broad experiences. These activities also allow for siblings to be involved in the same activities as their brother or sister with a disability.

#### List of current services

##### Bayview Disability Services

- *Flexible Support Packages; Making a Difference, Family Options*
- *RAPT (Respite and Part Time Care)*
- *Family Choice*
- *Individual Support Packages*
- *Continence Scheme*

##### MacKillop Disability Services (Metro)

- *Flexible Support Packages; Making a Difference, Early Choices*
- *Family Choice*
- *Support and Choice Planning*
- *Special Support Unit*
- *Respite and Recreation*



##### Chloe\* - Barbi Nightmare

*Chloe thinks of scary things, but is trying to be bright and happy. She lives with her Nan who she loves very much. She is 8 years and she loves going to school.*