FINAL REPORT

Review Current Responses to Meeting Service Needs of People With a Disability and the Effectiveness of Strategies to Support Families

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the Nucleus group

www.nucleusgroup.com.au

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EXECUTIVE SUMMARY

This project sought to identify service responses that could better meet needs at an earlier stage and/or lower intensity than current services, with particular emphasis on the deferral of full-time residential care.

The results of this research project will be of assistance in identifying current and future initiatives that have the potential to achieve a preventative, pro-active approach. Such approaches are likely to be more cost-effective and produce better outcomes for individuals, including increased independence and the maintenance of natural support networks and the family unit.

The project defined key components of successful responses to demand for services from across the human services sector that could be applied to the Australian disability sector. These features were grouped together into three general themes or approaches:

SERVICE COORDINATION

The organised coordination of elements of support to create service programs and systems has for some time been a popular approach to the delivery of human services, both around Australia and internationally. More contemporary approaches combine this with a sense of shared responsibility and partnership between government, communities and family, further emphasising the need for careful coordination.

Service coordination is enhanced through a highly individualised approach. Service coordinators need time to develop relationships and detailed understanding of a person's needs and circumstances; a strong local focus is also required - people who live in the geographic area in which they work can better match needs to available services and facilitate community development. The breadth of the coordinator's role is also important – it should include helping to determine needs and plans for future service requirements, assisting consumers to coordinate the provision of services, monitoring the quality and quantity provided, providing information and advocacy, supporting the development of strong informal networks, and providing "grass-roots" information to those responsible for policy and funding decisions. Care coordinators should have substantial devolved authority across the relevant components of the service system.

Increasingly, approaches to the provision of services are using central coordination mechanisms to provide access to a large and diverse range of services provided by a mix of community based, local government and commercial service providers. A single point of contact to identify needs, inform service planning and act for people assessed as needing a range of services from across different programs or sectors can be important in achieving coordination. Multi-disciplinary assessment teams that address the broad range of supports that families may benefit from, not just the disability-factors, can also contribute to better coordination of services.

Appropriate targeting of services both within and across service systems relies on an acknowledgment of multiple needs that require a range of strategies. Resources need to be targeted appropriately along a continuum of self-help to intensive supports in order to meet needs across a population, balancing a pro-active early intervention approach with responding to assessed or articulated needs. Furthermore, in disability services, both formal and informal supports may be required across the lifespan, through the life stages of childhood, adolescence, adult and senior and most importantly through the transition from one life stage to the next. It is not simply that people with a disability may need long-term support, but that the nature, intensity and level of support changes within and across life stages.

Other factors that can enhance service coordination include pooling of funds and the capacity to combine a range of grants in a package of measures, extending to flexible funding arrangements including providing funding directly to consumers to purchase services and supports.

Workforce development is another important area, including systems to recruit and support the most appropriate candidates for service coordination positions, and their ongoing personal and professional development. Accumulated experience (with services, service users and the community) is also a critical factor and steps should be taken to maximise retention of good workers.

In response to the unique service delivery and coordination issues for specific populations including people in country areas, indigenous people and people from culturally and linguistically diverse backgrounds, approaches should seek to transfer planning decisions to these communities with the flexibility to pool resources for community-level responses where appropriate and to develop tailored models of service delivery.

It should be noted that the extent to which outcomes can be achieved will vary according to context - factors such as geographic isolation, limited investment in local decision-making capacity, limited service options, workforce shortages and limited infrastructure will tend to inhibit progress. Notwithstanding this, understanding and measuring outcomes are essential factors in delivering effective services.

FAMILY SUPPORT

The provision of an extensive, flexible and individualised range of formal family supports has been associated with reduction in out-of-home placement of children with disabilities (Gordon 1999). A contemporary goal of providing support to individuals and families is to build resilience over the long term, reducing future need for more intensive services. In building family resilience, theory supports a focus on the needs of the total family, as it highlights the impact of features, events or changes in one part of the system on other parts of the system (Cooper et al, 2001).

In Australia, family support initiatives are an area of growing investment – most jurisdictions have introduced some level of support specifically targeted at supporting families and increasing their capacity to provide for a family member with a disability, as well as developing informal and community supports around the family.

Families with a child with a disability are likely to be accessing a range of services including specialist disability services and mainstream supports such as childcare, maternal and infant health services and home visiting. Providing holistic family support and early intervention services are the two broad program approaches to meeting the support needs of these families. Early support and intervention are clearly seen as highly effective in preventing or reducing the level of more intrusive interventions at later stages (AIHW, 1997).

Family support programs have the ability to address complex care needs including severe or multiple disability, challenging behaviour and where multiple, flexible service responses might be required. They can also recognise and respond to risk factors with regard to family coping or well-being and address urgent support needs or needs subject to rapid change which may be difficult to accommodate in other services. Family support programs also have a capacity to be provided across the lifecycle and can build capacity and resilience over the long term. Services should aim to be ongoing, including facilitating and developing long-term planning throughout the child's development through and into adulthood.

Participation in decision-making and control of services delivered is important in assisting families to gain expertise and skills. A goal of services should be the development of a framework that seeks to cultivate family problem solving, enhance and promote individual and family capabilities, and strengthen positive family relationships. Such a framework would feature family feedback as a central element. Families also need locally relevant information and support to access information where required, to assist them to understand the service system and acquire the services they need. This includes information about the nature and implications of their child's disability so that they may set reasonable expectations for the future.

Assessments should have a dual focus on individual needs and the needs of the carer or the whole family as a unit. This is consistent with research findings that supporting carers is critical to providing stable environments and maintaining informal supports. The care plan should be based on family preferences and choices, with a network of local providers consulted and involved in development of the care plan.

Where appropriate, care plans should particularly consider a place for models, technologies and training to assist families with management and prevention of challenging behaviours, and for flexible short-term care. Respite should be provided as part of a coordinated, integrated package of support for families, rather than as a single type of support provided only on an emergency basis. Services should be able to provide both regular planned respite and be responsive at short notice when unpredictable needs arise. Services should also be supplied in a variety of ways including facility based, host and in-home respite, paid carer schemes, outings and holiday programs, and service staff accompanying families on holidays.

From the service provider's perspective, coordinators should work directly with the whole family with contact planned and carried out at appropriate intervals, particularly if support needs are prone to fluctuation. As it can sometimes be the transition between life stages for the person with a disability rather than the stages themselves where family resilience is most tested, major events or transitions for the family unit as a whole should also be considered as important times to focus service responses. Optimum staff performance and the maintenance of consistency across the service requires high levels of supervision, teamwork, staff development and staff support.

INDEPENDENT LIVING

Approaches that encourage greater independence for the family and/or individual with a disability can contribute to better outcomes for service recipients and reduce or defer demand for more intensive, expensive services.

One way that independence can be increased is by transferring decision-making power to people with a disability and their families, to provide greater choice and flexibility and to facilitate a sense of autonomy and ownership. This may include consumers determining the nature of supports they receive, participating in the development of care plans or support packages, or selecting providers either through services or direct employment.

Increased autonomy and power in the hands of service users and caregivers can be achieved through mechanisms such as cash payments or vouchers to purchase services. Support for such initiatives should include the provision of assistance to help beneficiaries carry out their management tasks of recruiting, training, supervising, disciplining, and paying their workers; and the incorporation of a capacity for crisis response for individuals considered 'at-risk' or with urgent, high or complex needs. Such initiatives should also be underpinned by the establishment of cost benchmarks, payment rates and a system to assure the quality of care provided.

Other initiatives that promote independence include the regular review of an individual's support arrangements. This is important in predicting and responding to changing needs across the lifecycle, allowing for early intervention if problems arise. As few staff as possible should be involved with assisting the individual to plan their supports, and consistent and ongoing relationships between the service coordination staff and the individual are also important.

The capacity to provide appropriate back-up support (eg to counter a change in the daily routine of a family member with a disability that forces significant changes in other family members' routines) or an avenue of return to a 'safe-haven' if a new residential arrangement were to break down, are important in decreasing long term reliance on more formal, intensive forms of service.

If a service broker or coordinator is involved, their role should be defined with a view to encouraging and reinforcing independence. This may include teaching people and their networks about the resources and choices they have, helping to develop their budget, assisting to negotiate contracts, and monitoring to ensure that people's choices are being honoured and to assist if changes need to be made.

A strong market in assistive technology that will drive innovation, availability and reduce the costs of such equipment, will also promote independence amongst people with a disability. A part of such a system would be a large-scale approach to coordinating agencies providing assessment and advice in relation to technology or making information about products available to prospective purchasers.

Access to employment provides greater independence and economic resources for people with a disability, potentially leading to reduced dependence on formal services and reduced reliance on informal carers and families. As an adjunct to the mainstream employment services sector, specific strategies to promote self-directed employment for people with disabilities could be adopted. Strategies could include providing technical skills training, establishment of small business advisory services and a national program of work-based personal assistance for people who are self-employed, a pilot small business incubator catering for the special needs of people with a disability, or the provision of financial and material support, as well as marketing assistance and research. Encouraging home-based work arrangements, for some, may also help people with disabilities to gain and succeed in employment.

In the same way that the general population use a variety of services and resources to maximise independence, so too should people with disabilities. This includes increasing access to childcare services and adoption of a lifespan approach by health services that recognises the progression or consequences of specific disabilities. It might also include adapting systems other than social services, such as public transport services.

In the report, each of the three approaches summarised above is illustrated by a range of examples of actual service models drawn from an international literature review and a survey of Australian jurisdictions (the latter designed specifically to collect information pertinent to the objectives of this research project).

Each approach is also subject to more detailed analysis with the findings intended as a very practical guide for jurisdictions. The findings can be used for purposes such as review of existing services, or structuring new services, where a preventative emphasis is sought that will better meet needs at an earlier stage and/or lower intensity than more traditional alternatives.

A particularly important aspect of the analysis is cost effectiveness. While it appears that relatively little work has been undertaken to compare costs or consumer outcomes generated by different approaches to meeting a given set of needs (little data that could be used for such purposes was available from jurisdictions), approaches to delivering services that combine the features described above will reduce demand for services and produce substantial cost savings over full time residential care and other more intensive services. A number of examples are discussed that enhance outcomes achieved by individuals with a disability and their families and carers, and also generate cost savings to government over available alternatives.

INTRODUCTION

PURPOSE OF THE REVIEW

This ‘Review of Current Responses to Meeting the Service Needs of People with a Disability and the Effectiveness of Strategies to Support Families’ has as it’s focus the identification of responses that can better meet needs at an earlier stage and/or lower intensity than current services, with particular emphasis on the deferral of full-time residential care.

By implication, any shift in focus needs to be towards earlier identification, intervention and amelioration of potentially greater (and more costly) demands on the service system. Furthermore, any later responses are more likely to be needed as a result of a crisis situation (e.g. imminent breakdown in family care-giving) and therefore are less able to be predicted and implemented in a planned fashion.

Contemporary approaches to the delivery of welfare and health care services are based on a principle of shared responsibility and partnership between government, community and family. Such a principle recognises the interplay of individual, environmental and social factors in creating service needs; it also directs resources to meet these needs (through a strengths based approach) to building internal and external capacity and removing barriers to social and economic participation.

There is also increasing recognition that families are the primary source of long term care for people with a disability and that providing effective support to family carers is critical to future well-being and individual capacity. Many modern programs seek to build an expectation of ongoing flexible and community-based support and engage families early in the process in order to avert the need for crisis driven responses in the future. They also work to build the skills and capacity of people with a disability and caregivers to promote independent community living and employment participation over the lifecycle.

This research project seeks to identify workable, cost-effective responses that are consistent with contemporary research and social policy. Broader policy and abutting program areas (such as income support, health services and aged care) are also of interest as both part of the public supports available to people with a disability and as comparable approaches.

The results of this research project will be of assistance in identifying current and future initiatives that have the potential to achieve a preventative, pro-active approach. Such an approach is likely to be more cost-effective in the longer-term; it may also produce better outcomes for individuals, including the maintenance of natural support networks, the family unit and increased independence.

In the shorter term, a particular challenge for disability services administrators is the many families that have taken on the caring function for a member with a disability in a climate of limited access to services. The legacy of this effect is now being played out as demands for crisis responses increase through pressures that include the ageing of carers. Any benefits eventually generated through this research project may come too late for some of these families – they may continue to expect that intensive alternative care placements in accommodation support services such as residential facilities should now be available to them.

METHODOLOGY

The objectives of this project were to:

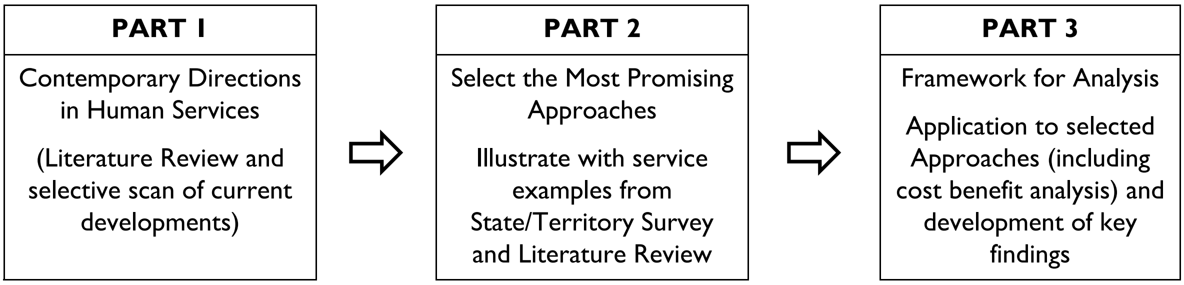
- Define the key components of successful systemic responses to demand for services (across the human services sector) that could be applied to the Australian disability sector.
- Identify emerging service models within and abutting the disability service system that demonstrate capacity to meet the needs of people with severe or profound disability at an earlier stage than current service options, including the capacity to reduce the intensity or duration of ongoing support.
- Evaluate selected approaches against a specified framework and determine the overall cost effectiveness of identified service models when compared with existing service options.

Preliminary information gathering was completed through a review of literature from Australia and overseas and a survey of Australian disability programs across CSDA jurisdictions (survey developed to collect specific information pertinent to this research project). The review of literature included published research, government reports and evaluations conducted in Australia and overseas, and descriptions of emerging or promising practices from CSDA jurisdictions and other sources.

Of particular relevance to this project is *Listen To Us*, conducted by the School of Social Work and Social Policy at the La Trobe University (Cooper et al 2001). *Listen To Us* is a substantial piece of work that includes a comprehensive review of literature to examine service responses that strengthen and support families with children with disabilities, and thus impact positively on their capacity to continue to care for the child at home.

An overview of the structure of this report is shown in Figure 1 below:

Figure 1: Project Overview



PART 1: SOME CONTEMPORARY DIRECTIONS IN HUMAN SERVICES

This section forms a contextual overview to our review of approaches that might improve effectiveness in meeting the needs of people with a disability and their families.

Material presented in this section has been drawn from a limited review of literature concerned with the delivery of disability services and other comparable services in Australia and overseas.

The key findings identified in this section have also contributed a foundation for a *Framework for Analysis* that is used later in this report to undertake more detailed investigation of particularly promising approaches.

UNMET DEMAND

Governments across Australia are aware of high-unmet demand for disability services. In Australia, a substantial review of services identified significant unmet need for a range of supports resulting in substantial growth in demand for accommodation services, respite care and lifestyle support or day programs (AIHW, 1997).

The Australian Institute of Health & Welfare (1997) identified the following factors contributing to this demand:

- Growth in the target group - people with a profound or severe handicap, particularly those aged 45-65 years and those of working age but not participating in the workforce.
- Ageing carers - the number of parents aged 65 years and over who are principal carers for people with a profound or severe handicap was projected to increase from 7,700 in 1993 to 9,000 in the year 2003.
- De-institutionalisation - between 1981 and 1993 the number of people aged 5-64 years with 'severe handicap' living in households rose from 244,100 to 349,100 while the number living in establishments fell from 27,000 to 19,200. The trend is even more marked for people under 30 years. There has been a related rise, since 1981, in the numbers of people in the CSDA target group living with their families.

In recognition of high unmet need, additional funding was allocated through the Commonwealth State Disability Agreement (CSDA). The Australian Institute of Health and Welfare (AIHW) has recently completed a review of the effectiveness of this initiative and areas of remaining demand.

Growth in demand and recognition of unmet need has also been identified in comparable international jurisdictions such as USA, Canada and Britain.

In both local and international jurisdictions, governments are developing strategies to increase the overall provision of services and supports to people with a disability, both in terms of level of services and extent of coordination.

Strategies include substantial new commitments to funding services and improving efficiency, innovation and competition in service delivery (USA Federal Government: Delivering on the Promise of Independence, 2000; UK Department of Health: Valuing People, 2001) and using private health insurance to fund some services (eg Managed Care in the USA). Additional funding is typically directed towards alleviating current pressures in the service system (eg responding to families in crisis) and increasing prevention and early intervention programs.

Key Finding

1. There is high-unmet demand for specialist disability services in Australia and comparable international jurisdictions. Efforts are now being directed to better management of demand however it is still early days and further research and analysis will be required.

CREATING PARTNERSHIPS

Developments across the field of policy and delivery of human services have seen significant changes in the relationship between public and private sources of assistance. Terms such as 'welfare pluralism' or the 'mixed economy of welfare' capture the essence of changes that see local authorities becoming 'enablers' instead of direct service providers, contracting care out to a range of private, voluntary and statutory authorities (Fine, 1995).

Developments in the provision of human services in Australia include:

- Introduction of service brokerage and case management.
- The ‘purchaser/provider split’ and competitive tendering.
- The introduction of user charges.
- The re-orientation of long-term care policies away from reliance on residential care towards a more broadly based system emphasising the principles of 'community care' with greater reliance on informal, usually family-based care.
- A marked shift towards the provision of support at home, accompanied by an increasing emphasis in assessment and targeting.
- Increased private sector and non-government agency involvement in service delivery.
- Partnerships between government, communities and families, rather than 'all or nothing' provision to a select group of people.

Of particular relevance to this project is the recognition of the social and economic benefits of 'shared care' or partnerships with communities and families to support informal care. This has seen increasing public policy interest in strengthening and supporting family based care across a number of human service sectors but particularly services for children, people with a disability and older people (Shaver & Fine, 1995, Dunst et al 1993). Quereshi & Walker (1989) identify three policy options for government's seeking to encourage family based care:

- *The enforcement of familial responsibilities for care through the withdrawal of public assistance and the enforced reliance on the provision of care by family members.*

  Shaver & Fine (1995) suggest that this option has derived from government reluctance to interfere in family relationships. However, they argue that there is no evidence to suggest that providing support results in reduced caring or responsibility on the part of families. The evidence from the USA Channelling Projects and Sweden's comprehensive social support system demonstrate that effective supports maintain and enhance family relationships and caregiving roles rather than putting them at risk.

- *Relieving informal caregivers of responsibility by providing alternative forms of support for those who depend on assistance.*

  This option has proven to result in sub-optimal care for people with a disability and government resources are too constrained to provide comprehensive and effective alternative care services to large populations (Shaver & Fine, 1995). Institutional care has also proven to be much more expensive than home based care across a number of jurisdictions and service sectors (Hollander 1999; ABS, 1998).

  Residential facilities for people with a disability are being systematically closed across the US, Canada and Australia, with some states in Australia already achieving zero placement of children or adults into institutional care (Kendrick, 2001; Cooper et al, 2001).

  National and international policy commitments and pressure from disabled people are causing the emphasis of disability policy to shift in favour of inclusive policies and strategies (Metts, 2000). Driving forces include consumer advocacy, recognition of the rights of people with a disability to full citizenship and the social benefits of inclusion, and the implementation of legislative commitments (eg a major impetus in the USA has been the Supreme Court decision Olmstead v L.C. 1999 that interpreted the Americans with Disability Act to place an onus on States to provide community-based alternatives to institutional care facilities).

- *The support of informal caregivers through the development of shared care approaches in which state, community and family work in partnership.*

  It is this option that is being widely adopted and supported in contemporary policy. There is evidence to suggest that public support facilitates an ongoing commitment from family members to providing care, secure in the knowledge that alternatives are available should the tasks of caring become too overwhelming (Thorslund & Parker, 1994 cited in Shaver & Fine, 1995). Shaver & Fine (1995) describe this as 'shared care' and, whilst there are a number of unresolved issues in this direction, they review two broad approaches to supporting informal carers:

  - Assist caregivers by undertaking some of the tasks that they might otherwise have undertaken on their own. (Reviews in the UK and Australia suggest that models such as home help, home nursing and more innovative schemes such as flexible home attendance, based on direct payments to individual clients, provide a way to share some of the physical tasks of caregiving. Respite care including in-home respite, centre based respite and residential respite can provide caregiver relief and refresh emotional ties between caregivers and recipients of care).

  - Pay caregivers through an allowance (eg the Carers allowance) to support informal caregiving. (There is some interest across human service sectors in compensating carers for the expenses incurred in the provision of care. However there is also reluctance to devalue the relationship between carer and recipient and to reduce formal support services by redirecting funds to direct payments).

There is evidence of both approaches in current disability programs in Australia, the USA, UK and Sweden.

A challenge perhaps unique to a small number of human service sectors and most characteristic of disability services is that both formal and informal supports may be required across the lifespan, through the life stages of childhood, adolescence, adult and senior and most importantly through the transition from one life stage to the next. It is not simply that people with a disability may need long-term support, but that the nature, intensity and level of support changes within and across life stages.

Lifespan perspectives attempt to take into account the changing roles, functions, obligations, development, resources and coping strategies of families and individuals over the lifespan (Grant, 2001a). Grant describes two alternative hypotheses to families coping with long-term caregiving:

- Family coping may become more difficult as the child ages and as families face support network shrinkage over time - the 'wear and tear' hypothesis.

- Families may adjust to caregiving over time and develop skills and competencies that help them to cope. If developmental stages can be anticipated and planned for, then families are more likely to feel more secure and it is probable that more tailored and effective interventions will follow - the 'adaptation' hypothesis.

What distinguishes the role of the carer of a person with a disability is the duration of care. Parent carers of people with severe or profound handicap in 1993 had, on average, been caring for considerably longer periods of time than other family, including spouses. It is estimated that of the 7,700 parents aged 65 years and over who were principal carers in 1993 almost half had been caring for a person with a severe or profound handicap for over 30 years (Madden et al, 1996).

Key Findings

2. Within disability services and across other human service sectors, the concept of 'welfare' is being reframed and new approaches include a sense of shared responsibility and partnership between government, communities and family.
3. Services and supports should seek to promote positive adaptation to caregiving rather than suggest they alleviate the 'burden' of caregiving.
4. There is increasing recognition that families provide the primary source of support to people with a disability - program administrators are becoming 'enablers' instead of direct service providers.

BUILDING FAMILY AND INDIVIDUAL RESILIENCE

There is substantial research both generic and specific to families that have a child with a disability, that seeks to examine the combination of factors (eg personal characteristics and contexts) that lead to vulnerability or risk, and which combinations offer protection from risk and boost resilience.

In terms of families with a disability, resilience seems to be related to the communication skills of family members, their capacity to be flexible, their degree of commitment to maintaining the family unit, their problem-solving abilities the extent to which they maintain their social networks and develop sound working relationships with professionals (Bowes & Hayes, 1999). There is increasing focus within human service programs to building the resilience of individuals with a disability and their families over the long-term, rather than simply meeting immediate or short-term needs or preventing risk occurring.

AIHW (2001c) defined family support services as "*services that seek to benefit families by improving their capacity to care for children and/or strengthening family relationships*". Family support services have evolved as an early intervention approach to child protection and social well-being. Family support services are becoming more publicly visible and politically and financially recognised. Child protection and family violence services are still extremely important and receive considerable funding from government, but are now increasingly complemented by services which build on the strengths which exist in families, rather than focusing on the dysfunctional aspects of family life.

Major categories of family support services include:

- Information and referral (eg parenting and family centres).
- Education and skills development (eg resource guides and skills development workshops).
- Counselling, mediation or therapy.
- Residential and in-home support (eg professional home visiting).
- Advocacy (eg parent networks, neighbourhood houses).
- Other family support services (eg play groups, self-help groups).

Increasingly these supports are being provided through holistic family support programs across a continuum of flexible supports for broad prevention and resilience building to intensive supports for families with high or complex needs or those considered at-risk. Significant components of family support services for families with a child who has a disability include early childhood intervention, respite care, parent education and empowerment, and behaviour intervention.

There is increasing recognition that families are the primary source of long-term care for people with a disability. In a review of personal relationships of support between adults with a disability and significant others, the Roeher Institute (2001) found that that these relationships of support are highly valued by both providers of support and adults with disabilities. The review also found that adults with disabilities are usually constructed socially and legally as passive and dependent recipients of care. However, research shows that they make significant economic, domestic and emotional contributions to the relationships of support that they are a part of. When these relationships are defined by interdependence, reciprocity, dignity and mutual respect, they bring health and well-being to both adults with disabilities and those providing care or support. Singer's 1996 review of literature on family benefits of caregiving includes increased life satisfaction, sense of purpose and positive feelings of self-satisfaction and accomplishment (Singer et al, 1996 cited in Roeher, 2001).

The permanency planning principle for children with a disability gives priority to keeping the child in the birth family. Through many parts of the USA, the permanency planning principle has been applied to children with disabilities. It also underpins the policies of Queensland and South Australia that some years ago chose to close residential services for children with disabilities and give priority to birth family support and family placement as the preferred alternative care model (Gordon 1999).

Werner (1984) states that permanency planning involves systematic case planning with the objectives of ensuring that the child has a consistent home, continuity and commitment in the child's family life; and that the family is one in which the child has a real sense of belonging with a 'respected' social status, in contrast to the 'second-class' citizenship, typical of temporary foster care.

Families with children with disabilities are under the same stresses and strains as all families. They have the same range of financial, employment, housing, health and relationship problems as in the broader community. Divorce, loss of a parent's employment, financial stress or insecure housing arrangements may lead to family breakdown, as in any other family.

In addition, families with children with a disability face a wide range of additional or more intense stress-causing experiences including behaviour problems, night-time disturbance, social isolation, difficulty in settling the child at night, problems with the child's health and/or appearance, and economic stress (see Cooper et al, 2001 for a more detailed discussion). Caring for a child with a disability can also affect the health of the caregivers and can sometimes cause serious depression and mental health problems.

Family systems theory supports a focus on the total family, as it highlights the impact of features, events or changes in one part of the system on other parts of the system. Turnbull and Turnbull (1990) describe a framework to appraise variables associated with stress and coping:

- Family variables - family socio-economic status; family cohesion; family hardiness; family problem-solving skills/creativity; family roles and responsibilities; and family composition.
- Parent variables - quality of marital relationship; maternal locus of control; parental appraisal; time and schedule concerns.
- Child variables - severity of disability; age of child; child gender; and child temperament/ social competence.
- External variables - stigmatising social attitudes; social network support; and collaborating with professionals.

Research by Blacher and Baker (1994) suggests that parents may be more reluctant to place very young children. However it also found some evidence that the major factors (eg perceived daily stress, severity of disability, behaviour problems) occurred independently of the child's age.

Llewellyn et al (1996) found three key factors influencing families' decisions about caring for a child with a disability at home or seeking alternative care:

- A lack of congruence between the needs of the child with a disability and other family members.
- A lack of integration of their child with a disability into their everyday family life and the community more generally.
- Concerns about the effect of the child with a disability on their siblings both now and in the future.

A number of authors cite research that suggests that once a family has reached the point of seeking out-of-home-placement it is difficult to provide effective supports to change that decision. It is typically a decision that has taken a long time to make and by then their capacity to cope with the child or adult may be very low and supports provided may be ineffective (see for discussion Seltzer & Krauss 1984).

The provision of an extensive, flexible and individualised range of formal family supports has been associated with reduction in out-of-home placement of children with disabilities (Gordon 1999). Comprehensive family support programs have been effective in reducing out-of-home placement (Wisconsin Department of Health and Community Services, undated, circa 1990).

Increasingly, systemic approaches to the provision of services are using central coordination mechanisms to provide access to a large and diverse range of services provided by a mix of community based, local government and commercial service providers. Excessive specialisation of services has been identified as a barrier to access by making service systems complicated and difficult to negotiate (Fine, 1997).

In Australia, family support initiatives are an area of growing investment - disability programs across State and Territory CSDA jurisdictions have all introduced some level of support specifically targeted at supporting families and increasing their capacity to provide for a disabled family member as well as developing informal and community supports around the family.

Grant (2000; 2001a) recognises that there may be some issues with caregivers striking a balance between protection and community inclusion, particularly opportunities outside the home as caregivers age. This may be in part a function of a lack of inclusiveness in service systems such as education, health and social services over the time that they have been providing care. This can be prevented in future by encouraging early access to formal supports and appropriate skills development.

Family carers may not seek assistance until they reach a crisis in their care provision. This needs to be addressed by service systems through proactive early intervention and prevention strategies.

Grant (2000, 2001a) also describes some differences in carers over the lifespan. Parents with pre-school children may be less sure about their experience and expertise as carers and less assertive with their child, they may rely more heavily on stress alleviation than other carers. Parents with school-age children and younger adults are more likely to place greater emphasis on problem-solving methods, have greater confidence in their own capacity and expertise as carers and may be better at dealing with situations due to more demands on their resources resulting from other children, employment or training etc. Family carers supporting disabled relatives aged 40 years or over may be more resigned to their role, place less emphasis on information seeking and generally accept the way things are. However, older carers also report feeling that they should have been more assertive in the past to get the supports that they want.

Treatment programs for children with a disability have traditionally focused on the child and the primary care parent - typically the mother. The needs of siblings are often not well considered or addressed. Parental concern regarding the impact of having a child with a disability often includes worry that other siblings miss out on opportunities and parental involvement due to the high demand of caring for the child with a disability. Another group generally left out of program design and delivery is Fathers. Several researchers dealing with children with a disability note that the word 'parent' seems synonymous with 'mother'.

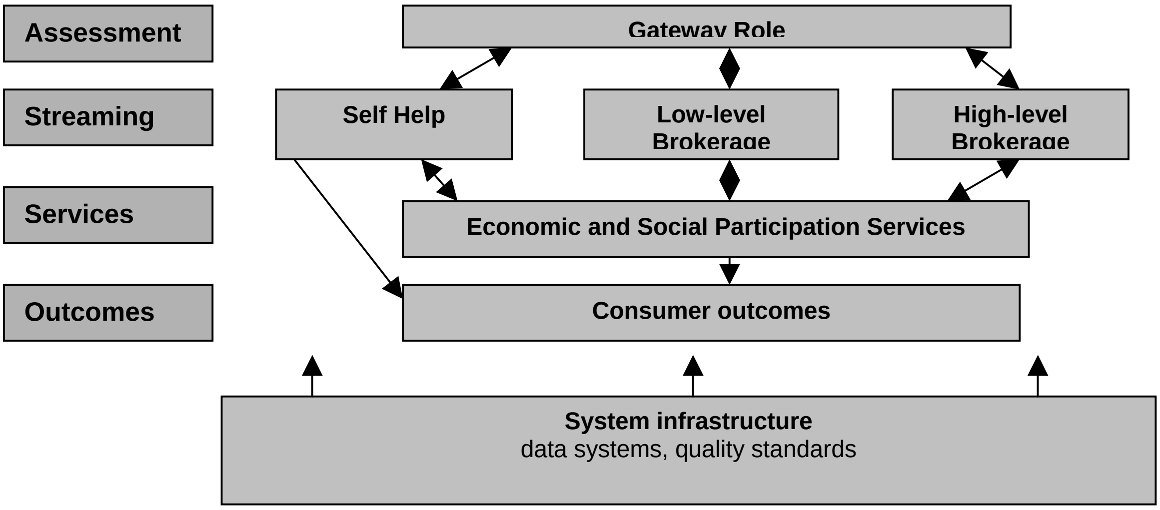
Key Findings

5. A contemporary goal of providing support to individuals and families is to build resilience over the long term, reducing future need for more intensive services. In building family resilience, theory supports a focus on the needs of the total family, as it highlights the impact of features, events or changes in one part of the system on other parts of the system.
6. Increasingly these supports are being provided through holistic family support programs across a continuum of flexible supports for broad prevention and resilience building to intensive supports for families with high or complex needs or those considered at-risk.
7. Whilst the nature, intensity and level of needs will change within and across life stages, it is of importance that appropriate supports be available during *transition* from one stage to the next.
8. Family and caregivers should be supported in a way that facilitates an ongoing commitment from them to providing care, secure in the knowledge that alternatives are available should the tasks of caring become too overwhelming.
9. Family carers may not seek assistance until they reach a crisis in their care provision. This needs to be addressed by service systems through proactive early intervention and prevention strategies.

TARGETING SUPPORTS ACROSS LEVELS OF NEED

Meeting the needs of a large and diverse population group (eg people with a disability, older people, families and children) requires a mix of approaches with strong links between preventing and responding to need, and targeted programs to specific groups or specific needs within the population. For example, the diagram below identifies three streams of approaches to addressing need across the population of people receiving income support (as described by the Reference Group on Welfare Reform, 2000, to outline a proposed service delivery system of the future):

Figure 2: Components of Service Delivery Systems



Appropriate targeting of services both within and across service systems relies on an acknowledgment of multiple needs that require a range of strategies. It is also important to recognise that these are not in competition but rather interactive and require appropriate balance (see for example: National Ageing Research Institute & Bundoora Extended Care Centre, 1999).

This might be seen as a continuum along which program goals may be defined and integrated into the broader response. The goals of the program and the need to manage demand for services within capped resource allocations, necessitates clear identification of the target group and eligibility criteria within and across systemic approaches. The program goal is set in a context of abutting programs that may be addressing different needs or higher/lower levels of need along the same continuum. An example of the continuum in practice is the comparison provided below between Home and Community Care (HACC) and Community Aged Care Packages provided to older people through the Commonwealth Department of Health and Aging:

Figure 3: Comparison of HACC and CACPs

	Home and Community Care (HACC)	*Community Aged Care Packages (CACPs)*
Range of services[a]	Wider range of services available	Narrower range of services available
Eligibility	Determined by service providers in line with program guidelines - no external assessment required.	Aged Care Assessment Team (ACAT) assessment is mandatory for the allocation of a Package.
Funding	Cost shared by Commonwealth, State and Territory governments and client contributions. Mainstream HACC agency funding is increasingly tied to the delivery of service outputs	Funded by the Commonwealth and client contributions. Fund holder can spread the available resources among high and lower need clients.
Target client groups[b]	Available to people with a greater range of care needs	Targets people with low level care needs similar to residential low care
Size of program	$865 million funding in 1999-2000	$150 million funding in 1999-2000
	About 49 000 clients in 1997-98	About 16 600 clients in 1999-2000

[a] HACC services such as community nursing, which are not available under CACPs, can be supplied to someone receiving a CACP.

[b] Most HACC recipients at the lower end of the scale would not be assessed as eligible for residential care; for example, an individual may only receive an hour of home care a fortnight. At the higher end, some people have levels of need that exceed the level available under CACPs.

Table and notes adapted from SCRCSSP (2001)

Key Finding

10. Contemporary approaches recognise the need to target resources appropriately along a continuum of self-help, low-level brokerage and intensive supports to meet the needs across the population, balancing a pro-active early intervention approach with responding to assessed or articulated needs.

PROVIDING CHOICE

People with a disability are increasingly recognised as having a central role in the development, delivery and evaluation of policy and services. "*It is anticipated that in the future people affected by disability have a role in shaping their environments and in managing the supports and services they require*" (NIDRR, 1999).

The Roeher Institute (1993) describe a contemporary framework for social well-being for people with a disability as one that has strong commitment to individual and collective self determination for people with a disability. This includes recognising the need to foster and resource the development of self-determination.

Strategies to improve choice and independence include increasing access to direct payments and flexible funding (UK Department of Health, 2001). A move towards flexible, individualised and local responses to the needs of people with disabilities, their families and their carers is clearly embodied in the service models now being developed and implemented across Australia (SCRCSSP, 2001). The Commonwealth is currently trialing a case based funding model for employment assistance while at the State and Territory level, individualised and localised responses to people's needs have been evidenced through various programs such as Local Area Coordination and Post School Options (SCRCSSP, 2001).

Systematic approaches to building resilience in families and individuals are developing service systems and models that are consumer-directed and provide individual autonomy over the supports provided. This may include consumers determining the nature of supports they receive, participating in the development of care plans or support packages, or selecting providers (either through services or direct employment).

Concerns and issues surrounding individualised supports include safety and quality of supports, costs associated with coordination, service viability and maintaining diversity of supports available. Service systems need to incorporate appropriate protection through monitoring and evaluation to ensure that people with a disability are not worse off under individualised approaches.

The reality of choice requires not only a commitment to individualised funding arrangements but also to ensuring that an appropriate range of services are available to choose from. System components designed to protect consumers through approval mechanisms for agencies from which services are purchased, can limit consumer choice. For example, Metzel (2001) surveyed State Administrators in the USA to explore to use of consumer-directed funding for employment and day services for people with developmental disability. While 50% of respondents reported the availability and use of consumer-directed funding for day and employment services, half of those also reported that funding could only be used with authorised vendors (predominantly state authorised).

Key Finding

11. Increasing choice and consumer autonomy is a significant factor in building the resilience of families and individuals and creating more flexible, responsive service systems.

IMPROVING ACCESS FOR SPECIFIC TARGET GROUPS

Individuals and families in country areas can experience more difficulty in obtaining services and may have reduced access to brokerage services to purchase in these areas (Cooper et al, 2001). Services can be more costly to provide in country areas and there may be difficulty recruiting and maintaining specialist staff. In some cases access to services may require extensive travel or may result in re-location away from family or social support networks.

Within indigenous groups there is evidence of low usage of services (Intellectual Disability Services Council 1998; Committee on the Evaluation of Quality Services for People with Disabilities 2000). The 1996 review of the CSDA found that relatively little is understood about the needs of Aboriginal and Torres Strait islander people with disabilities (especially those in remote communities). There is also a lack of literature and examples describing successful approaches (Cooper et al 2001) and higher rates of disability and unmet need (AIHW, 1997). Together, these create a strong case for improving systemic responses to Aboriginal and Torres Strait Islander populations.

The Uwankaraku Meeting, held in a remote aboriginal community in 1995 (NPY Women's Council, 1995) identified the need for local ownership and increased access to housing, maintenance and modifications; accessible transport (diesel

4WD); physiotherapists, exercise rooms and equipment to maintain physiotherapy; local homes for disabled people so that they are not removed from the community and sent to urban areas; more information and training on disability; help for individuals and families with basic tasks such as gathering firewood, showering, cooking, taking people into town for health services. There was also considerable interest in access to equipment for people with disabilities, particularly equipment that has been adapted for living in remote areas.

Strategies to increase access for indigenous people must recognise and respond to strong cultural attitudes to caring: for example, some carers may be reluctant to apply for payments such as the Carers' Payment, or they may have an expectation of the duty of caring as a natural role (Qld Council of Carers 1999). A Queensland evaluation of the national Aboriginal and Torres Strait Islander Carer Support Kit found that working through community leaders and face-to-face contact are essential to disseminating information and developing meaningful relationships for service provision. The report also recommended cross-cultural awareness training for all staff of services that have any contact with members of indigenous communities.

Llewellyn et al (1996) reviewed literature focussing on issues related to families of children with a disability who are from a non-English speaking background (NESB). Recurrent concerns over the last decade for families of children from a NESB who have children with a disability included the low use of services, the lack of culturally appropriate services, the absence of NESB consumers on management committees, the lack of linguistically appropriate information, and the need to educate service providers on cultural issues.

Differences in social support structures, responses to disability and engagement with service systems mean that issues for specific cultural groups will vary. A good description of the range of issues that may arise can be drawn from the findings of the Inner Western Region Migrant Resource Centre study of the experiences of Vietnamese families with a child who has a disability (Nguyen et al, 2001). Language and communication barriers caused difficulties accessing formal supports while cultural beliefs resulted in restricted access to informal supports.

Lynch and Hanson (1992) provide a framework for gaining cross-cultural competence, through cultural self-awareness, developing culture-specific awareness and understanding, and developing competence in cross-cultural communication.

The Supplementary Services Program within the Commonwealth Child Care Program has improved access to childcare services for children with additional needs including children from non-English speaking backgrounds. This may entail workers in defined geographic areas, specialising in cultural responsiveness or particular special needs groups (including children with a disability and indigenous families). They may provide a range of supports to childcare services including training to assist appropriate planning and practice, individual child or family assessment, and developing information for specific cultural groups.

Key Finding

12. In response to the unique service delivery and coordination issues for specific populations including people in country areas, indigenous people and people from culturally and linguistically diverse backgrounds, systemic approaches should seek to transfer planning decisions to these communities with the flexibility to pool resources for community-level responses where appropriate and to develop tailored models of service delivery.

ADOPTING A STRENGTHS BASED APPROACH

Underpinning contemporary approaches is a new paradigm of disability, which might be considered a 'strengths-based' approach, replacing the historical 'deficits' approach to disability. The US National Institute on Disability and Rehabilitation Research (NIDRR) provides a good overview of the differences between these two approaches, summarised in the table below:

Figure 4: Contrast of Paradigms (Reprinted from NIDRR, 1999)

	"Old" Paradigms	**"New" Paradigms**
Definition of Disability:	An individual is limited by his/her impairment or condition	An individual with an impairment requires an accommodation to carry out life activities
Strategy to Address Disability:	Fix the individual, correct the deficit	Remove barriers, create access through accommodation and universal design, and promote wellness and health
Method to Address:	Provision of medical, vocational, or psychological rehabilitation services	Provision of supports, (e.g., assistive technology, personal assistance, job coach)
Source of Intervention:	Professionals, clinicians, and other rehabilitation service providers	Peers, mainstream service providers, consumer information services
Entitlements:	Eligibility for benefits based on severity of impairment	Eligibility for accommodations seen as a civil right
Role of Individual:	Object of intervention, patient, beneficiary, research subject	Consumer or customer, empowered peer, research participant, decision-maker
Domain of Disability:	A medical "problem"	A socio-environmental issue involving accessibility, accommodations, and equity

The International Classification of Impairments, Disabilities and Handicaps (ICIDH), published by the World Health Organisation has been revised to conceptualise disability as a multi-dimensional experience for the person involved. There may be effects on organs or body parts and there may be effects on a person's participation in areas of life. Correspondingly, three dimensions of disability are recognised in the draft classification: body structure and function (and impairment thereof), activity (and activity restrictions) and participation (and participation restriction). The classification also recognises the role of physical and social environmental factors in affecting disability outcomes (SCRCSSP, 2001). The inclusion of consideration to environmental factors and the need for assistance or supports captured in the revised WHO definition have been adopted in Australia (Australian Bureau of Statistics 1998 Survey of Disability, Ageing and Carers; Commonwealth/State Disability Agreement, 1998).

Defining disability as a contextual variable, dynamic over time and circumstance, changes the way that we might approach the provision of services and supports to address the needs of people affected by disability. This is not a simple shift from individual factors to environment factors, but rather recognition of the "*dynamic interplay between people and environment; of the adapting process, by the society as well as by the individual; and of the adaptive changes that occur during a person's lifespan*" (NIDRR, 1999). For example *"a person with quadriplegia who lives in an accessible house, has appropriate assistive technology, including a lift-equipped van which the individual drives, and has a support system of family and friends is likely to have fewer personal assistance needs than a person with less significant disabilities who lives in an inaccessible house, has no assistive technology, does not drive and has no informal or family support system in place*" (National Council on Disability (USA), 1996).

International commitments to human rights for people with a disability are now based on a philosophy of equalising opportunities through a commitment to removing and preventing social and environmental barriers that have traditionally restricted access for people with disabilities to social and economic opportunities (Metts 2000).

Fulfilment of this commitment requires an expansion of disability policies and strategies to include not only traditional rehabilitation and anti-discrimination measures but also affirmative strategies to prevent and remove social and environmental barriers. This is reflected in the United Nations *Standard Rules on the Equalization of Opportunities for People with Disabilities*; it is generally accepted that the American's with Disability Act contains the most comprehensive statutory requirements for accessibility, while legislative frameworks in Denmark and Sweden are the most comprehensive in Europe (Metts 2000).

As the Swedish Ministry of Health & Social Affairs (2000) states: *"A disability becomes a handicap only when the disabled individual comes up against shortcomings in the environment or in the organised activities of society. When measures are taken to make good these deficiencies and improve accessibility, the handicap can diminish or disappear. Disability policy must be based on this fundamental insight. Most environments and activities in our society affect people with disabilities in one way or another. For this reason it is virtually impossible to isolate disability policy from any other area of policy: it must permeate all spheres and all sectors of society."*

Achieving accessible environments is an ongoing challenge for governments. The Swedish Ministry of Health and Social Affairs (2000) identifies that despite having legislation to improve accessibility since 1966, the pace of change has been too slow and the accessibility of public places, buildings, articles for everyday use and IT products/services remains unsatisfactory. The Swedish government is establishing a national accessibility centre to serve as an advisory body for accessibility issues and to implement stronger requirements in the areas of town planning and building codes, housing, transport etc.

In the USA substantial new commitments to increasing the availability of assistive technology for people with a disability is a feature of the federal governments' *New Freedom Initiative* (2001).

In Australia, a number of jurisdictions have developed Disability Action Plans to improve access for people with a disability across government activities. This concept has its genesis in the Commonwealth's Disability Discrimination legislation and is reflected in some state disability legislation.

At the service level, mechanisms for creating more accessible and supportive environments may include linking cross-government activity, providing funding or expertise to aid the purchase equipment or adapt housing or vehicles, referral or coordination of other services (eg special needs teachers or resources in early childhood settings), increasing community awareness, or advocacy on behalf of people with a disability in relation to universal design or improved accessibility.

Research has found that disability (and risk of disability) are disproportionately concentrated in specific populations: those in poverty, those who lack access to state-of-the-art prevention or interventions, and those who are exposed to additional external or lifestyle risk factors (NIDRR, 1999). Furthermore, it has been widely recognised that people with a disability experience high rates of poverty and have limited employment opportunities, increasing their dependence on social programs (Reference Group on Welfare Reform, 2001).

In a comprehensive review of the economic circumstances of people with a disability in Canada, Fawcett (1996) found that living in a household with other people reduced the likelihood that adults with disabilities would be poor. Among adults with disabilities who lived in a household with other people, the poverty rate in 1991 was 16.5%; among those living alone, the poverty rate was almost three times higher at 45.5%. Women with disabilities were most disadvantaged by living alone – nearly half of those who lived alone, lived in poverty.

Fawcett (1996) also found that living with other people, in comparison to living alone, seemed to facilitate labour force participation among persons with disabilities. Possible reasons for this include that people who live with others are less likely to be living in poverty and unable to finance the costs of looking for or attending work; or that the social support network of living with others is likely to provide practical and emotional support to enable workforce participation.

In addition, people with disabilities must often spend additional money for items and services related to their disability. Disability-related costs can include medication, modified transportation, aids and assistive devices, and housing modifications. The additional costs of disability have been partially recognised by governments but largely remain the responsibility of the individual with little direct financial assistance (Welfare Reform Group, 2000; Fawcett, 1996). For individuals living on very low incomes, it may come down to a choice between purchasing these needed items or services and providing other necessities of life. In some cases, expenditures on these items may also mean the difference between being able to find a job or not. Without special aids, special transportation and other supports and services, some persons with disabilities may be unable to look for work, may be disadvantaged in competing for work or unable to perform the work.

People with a disability can therefore become caught in a poverty trap. This trap is best exemplified by social assistance programs that link supports and services to income support for persons with disabilities. Under such programs, assistance for required supports is available, but in order to acquire this assistance, persons with disabilities must often "trade a valued status (employable) for an unvalued status (unemployable)" (The Roeher Institute, 1993). For this reason, proposals have been made to establish a program of supports and services for persons with disabilities that is not linked to the welfare system. One of the most noteworthy proposals has come from The Roeher Institute: *"The system would not be a basic income support program. Instead, disability-related policy and programs would be removed entirely from a welfare framework. This would give an alternative to the many people with disabilities who have no option but to apply for welfare in order to qualify for essential disability supports, such individuals would be able to qualify for the attendant services, personal support workers, wheelchairs and other supports they require without program criteria that deny them access to the labour force, adult training, educational upgrading and other social and economic opportunities that are available to the non-disabled public" (The Roeher Institute, 1994).*

Key Findings

13. Disability is a contextual variable that changes over time and is a function of the dynamic interplay between people and environment. Shortcomings in the environment or in the organised activities of society can create barriers for people with a disability and give rise to needs such as services and supports.
14. Disability policies and strategies are being expanded to include not only traditional rehabilitation and anti-discrimination measures but also affirmative strategies to prevent and remove social and environmental barriers.
15. Approaches that address underlying causes and environment factors when responding to individual needs will be more effective over the long term.
16. Systems should address poverty through increasing both financial and social supports, meeting the additional costs of disability and ensuring that entry conditions for supports that promote social and economic participation do not perpetuate a poverty trap.

SUPPLY-SIDE MANAGEMENT

Addressing high unmet need through improved responses and better management of both demand and supply is a common theme across human service sectors. A brief analysis of two comparable sectors is provided below.

Aged Care

Australia has a substantial and growing older population. Partly in recognition of the preferences of older people for living independently, and also on account of the large projected increase in the size of the older population, the Commonwealth government initiated a process of aged care reforms in the mid 1980s. This included the expansion of home-based care services and hostel (or low care) accommodation, and a reduction in the proportion of older people being placed in nursing home (or high care) accommodation.

A significant feature of the reforms was the introduction of Aged Care Assessment Teams that provide an objective, public, multi-disciplinary approach to screening applicants for nursing home care.

For people living at home, the major services funded include the Home and Community Care (HACC) program and Community Aged Care Packages. Between 1985/86, when the aged care reform process started, and 1995/96, expenditure on HACC services increased their share of total recurrent aged care expenditure, reflecting the shift away from funding for supported accommodation. This period also saw the introduction of Community Aged Care Packages, which provide an intensive level of home care with the aim of enabling as many older people as possible, even those with more complex care needs, to remain at home. Also reflective of the change in emphasis from the more intensive forms of residential care, hostels increased their share of total aged care expenditure between 1985/86 and 1995/96.

By increasing access and the coordination of home and community based supports the Aged Care Program successfully changed the pattern of service delivery. The number of people entering residential facilities is declining and the age of entry is increasing.

Early Childhood Education and Care Services

Early Childhood Education and Care Services include preschools, kindergartens, outside school hours care (primarily State/Territory funded) and child care services including long day care, family day care, mobile services, in-home care and multi-functional services (primarily Commonwealth funded). Australia relies upon a mix of for-profit and non-profit providers. The Commonwealth has recently introduced the Child Care Benefit that is a means-tested payment to families to subsidise user fees for the cost of child care which may be purchased from approved formal service providers. Alternative subsidies are also available for the provision of informal care (family, neighbours etc).

Around the nation, the impact of greater attention to the early years is evident in policy and practice. The increase in international research on the importance of the early childhood years to children's future well-being and development has resulted in a greater focus upon the needs of young children. In Australia, information from such research has contributed to a number of reforms in areas concerned with the early years, and to a greater degree of interdepartmental collaboration and exchange.

For almost the decade prior to 1991, the supply of childcare places through Commonwealth funding was subject to a needs based planning process and all funding was available only to the community-based non-profit sector. During this time, demand for childcare places far outweighed supply. In 1991, the supply of long day care centres was transformed with the granting of fee subsidies to families using the private sector. This change in policy provided a stimulus to private sector investment. Uneven and unforeseen growth resulted, with some areas experiencing an oversupply of places, whilst demand and gaps in supply still existed in some regions.

In 1997, in an attempt to address issues of unplanned growth, a planning mechanism was introduced which capped the number of new long day care places for which fee subsidy would be available to 7,000 a year, over two years. This cap has since expired. The Commonwealth proposes to address the issue of oversupply by providing information to potential investors on regional supply issues, including advertising high need areas and providing information on areas of under and over supply to prospective operators, local governments and financial institutions. Provisions in the new Family Assistance Legislation, which took effect from 1 July 2000, enables the Commonwealth to again limit the number and location of new childcare places in the future, if necessary.

Although regional oversupply is an issue, so too are pockets of undersupply. In rural and remote areas this issue has been partially addressed through targeted funding, such as the Disadvantaged Area Subsidy Program that provides support to assist services in some rural and urban fringe areas. A more recent focus of the Commonwealth has been to provide financial incentives to private for-profit long day care operators to establish services in rural and remote areas that are undersupplied and to introduce in-home care services for families where other forms of care are not available.

Key Findings

17. Addressing unmet need can involve strategies that include limiting or changing supply (financial incentives, earlier intervention or partial supports rather than 'all or nothing') and changing demand for services by addressing the causes of the need (individual and environmental).
18. Easier access to community and home-based support can act as alternatives to residential placement.

EARLY CHILDHOOD INTERVENTION

Families with an infant or pre-school age child who has a disability are often coping with substantial adjustment, emotional responses to the disability and increased caring responsibilities. They are likely to be accessing a range of services including specialist disability services (eg therapy services) and mainstream supports such as childcare, maternal and infant health services, home visiting etc. Providing holistic family support and early intervention services are the two broad program approaches to meeting the support needs of these families.

The *Family Resilience Project* identified early intervention as an area where resources could be focused for best results. Early intervention, intensive family support and specific behavioural intervention strategies are all important responses to mitigate the problem of challenging behaviour and its potential to precipitate out of home placement. "*There is a clear demand, supported by evidence from the literature, for early intervention services which fit within the framework of primary level prevention. It is at this level that families can be supported in their roles and the nurture and development of the child with disability*" (Cooper et al, 2001; Roberts et al, 2001).

Early intervention is often cited as vital support for families with an infant or young child that has a disability or chronic health condition. This is seen to aid the grief and loss process commonly encountered and to also enhance child development and family survival. Early intervention services create space for families to get together, and may help to prevent parents blaming themselves for behavioural problems.

Components of support provided within early intervention models include:

- Help to understand their child's condition and working with doctors and medical specialists and other sources of knowledge, skills and experience.
- Taking care of individuals within the family, including self and family relationships, partners in two-parent households, extended family, individual impact on mothers and fathers, and siblings.
- Coping with (including obtaining support for) their own feelings about having a child with a disability and those of friends and the general public.
- Finding out about services and using the service system.
- Acquiring and managing financial resources and physical resources to care for the child's health problems (such as medical equipment or assistive technology) and coordinating the management of the care of the child.
- Establishing and managing effective social supports.

(Adapted from Cooper et al, 2001).

Key Finding

19. Early support and intervention are clearly seen as highly effective in preventing or reducing the level of more intrusive interventions at later stages (AIHW, 1997).

PARENT EDUCATION AND EMPOWERMENT

The Family Resilience Project identifies as a priority the need for parenting skills education and resource materials to be available to parents of children with disabilities as part of parenting skills education available to all families (Cooper et al, 2001). Families need information to understand the cause, nature and implications of their child's disability in order to set expectations for the future and to begin to regain some control over their lives (Roberts 1986).

Parents need models and mentors. Michigan and other US states have created parent training programs that are developing and disseminating these skills (Thompson et al, 1997). Dempsey (1996) describes a self-advocacy initiative designed to explicitly empower families that provided training, information, resources, and skill building in the area of developmental disabilities to families of young children with disabilities and to consumers with disabilities.

The role of parent support groups (which may take a variety of forms) can be pivotal, in providing support, information and individual advocacy. Mutual support networks with a paid coordinator (often a parent with relevant skills) are an established part of the family support service system in a number of overseas countries and in some parts of Australia. In Victoria, these networks are regionally based and offer mutual support, group activities which may provide information and training (Liesis 1988) and also provide a forum for emotional support, sharing of ideas and information about daily care of the child (Cystic Fibrosis Victoria 1999a).

The Parent-to-Parent Model (USA) links individual parents with another parent for support purposes (Turnbull & Turnbull 1990; Powers 1996). Funding usually covers the salary of a paid coordinator whose role is to recruit and train parents for this role.

Brodie (1995) discusses the increasing number of resources available to families of children with disabilities via the Internet. Both in Australia and overseas, newsgroups for families exist, some related to specific disabilities such as Down syndrome. Through newsgroups and email contact, families may gain information and emotional support; information can also be accessed via worldwide web sites of a wide range of disability organisations and groups.

Families should also have access to locally relevant information and support where required, to assist them to navigate the services system and coordinate the services they require (Cooper et al, 2001).

Key Findings

20. Families need information to understand the cause, nature and implications of their child's disability in order to set reasonable expectations for the future and to begin to regain some control over their lives (Roberts 1986).
21. Modern service programs seek to transfer decision-making power to people with a disability and their families, to provide greater choice and flexibility and to facilitate a sense of autonomy and ownership.

PROFESSIONAL COMPETENCE

One of the difficulties with family support initiatives is that parents can find the behaviour of professionals as disempowering, intrusive in the home, and not necessarily supportive or competency enhancing. Service providers frequently do not communicate effectively and/or do not have adequate knowledge in relation to the disability, its impact on the family and the needs and rights of the family.

A number of authors have suggested that the single most important factor in a good quality service was the relationship between the individual worker and the service user (Allen & Potten 1998:5, drawing on Beresford et al, 1997).

Parents appreciate professionals who value their children and make a relationship with the child, take account of total family needs, respect their competencies and work with them as partners (Joseph Rowntree Foundation 1998; Chenoweth, 1997; Petr et al, 1995).

Professionals may fail to recognise the coping strategies that families have developed. Cognitive coping strategies such as reframing the significance of challenges, decision-making and problem solving, are often underestimated by professionals (Grant, 2001a).

Key Findings

22. Across a range of disciplines and service needs, researchers are highlighting that it is *how* programs are delivered as much as *what* programs are delivered that impact on consumer outcomes.
23. Professionalism in providing family support services is increasing, with resourcing, training and support for both professional staff and volunteers receiving greater attention and funding (AIHW, 1997).

IMPLEMENTATION CONSIDERATIONS

The Steering Committee for the Review of Commonwealth/State Service Provision (1998) developed a checklist for implementing reforms in government services from a review of five case studies of major program reforms (including the introduction of local area coordination and direct payment funding in WA). The checklist includes considerations under the following areas:

Decentralised Decision-Making

This entails shifting responsibility for how to provide particular services to a lower level and should be preceded by consideration of whether decisions should be delegated or devolved. Delegation may be appropriate where staff that deal with clients are best placed to decide how services should be provided, or when it is appropriate to separate policy making (eg type and level of services to be provided) from administration (choosing who should receive services). Devolution may be appropriate where consumer preferences vary widely and the central agency is unlikely to be able to offer sufficient choice or flexibility, or when non-government operators are able to make more efficient/effective use of government resources.

Measuring and Assessing Performance and Quality

Some service reforms (eg decentralising decision making) increase the importance of effective mechanisms to monitor performance. Performance indicators are a key accountability mechanism and provide valuable information on the effectiveness of reforms. Issues in developing performance measures include defining service outcomes, establishing benchmarks, avoiding a narrow focus on measurable outputs to the detriment of broader qualitative outcomes, data collection and analyses, deciding the relative importance of conflicting goals, and recognising the point at which increasing precision in measurement outweighs the benefits of likely improvements.

Performance indicators covering service quality are needed to remove the temptation for service providers to reduce quality as a way of improving other measurable indicators of performance. Issues include choosing the most important aspects of service quality, designing measures and determining who is best placed to measure each dimension of quality (whether clients or their guardians, external assessors, providers of services or the government agency purchasing the service).

Linking Funding to Performance

Monitoring mechanisms should be supported with appropriate rewards and sanctions, including a link between funding for service providers and their measured performance. Issues include defining outputs or outcomes that are funded (and ensuring that providers can directly control these outcomes or outputs), measuring performance with reliable and comparable information regarding the costs of different outputs, recognising variations in client need and provider characteristics and the impact on costs, and determining an appropriate frequency for review.

Consumer as Purchaser

Implementing user charging involves a number of important steps such as identifying and measuring the costs of the service, determining the desired level of cost recovery and choosing whether to implement user charges gradually or more rapidly.

Charging fees for disability services occurs across a range of service models including accommodation, recreation and respite services. However, any further introduction or expansion of fee charging may need to consider the fact that both individuals and families of people with a disability have a higher than average rate of poverty, reduced income capacity and unemployment (ABS, 1998; Fawcett, 1996).

Key Findings

24. Decentralised decision-making can produce more effectively tailored services.
25. Understanding and measuring outcomes are essential factors in delivering effective services, with a sustained move towards identifying outcomes for individuals, families and communities (AIHW, 1997).

PART 2: APPROACHES & SERVICE MODELS

Research to this point in the project has identified a range of features of contemporary service systems that appear to assist services to better meet the needs of families and individuals. Many of these features can be grouped together into general themes or approaches to meeting the needs of people with a disability and their families that may also prevent or delay the need for more intensive supports.

This section of the report illustrates three such approaches with a number of relevant service examples (drawn from current disability services and abutting systems both within Australia and overseas via a literature review and survey of Australian jurisdictions). Service examples have been selected to demonstrate particular *components* of the approach, not necessarily to exemplify the approach in sum.

Service Coordination

PLANNING FRAMEWORKS

Broad planning and policy frameworks for the delivery of disability services in CSDA jurisdictions can take the form of a Disability Services Strategic Plan or Disability Action Plan.

Disability Services Strategic Plans have been developed by the Commonwealth and all State and Territory jurisdictions. Within these frameworks there is increasing emphasis on building the strength of individuals, families and communities. Strategies to achieve this include programs that provide more flexible supports, target the whole family and possibly broader community networks, and work to achieve economic and social participation outcomes.

Disability Action Plans have their genesis in the Commonwealth's Disability Discrimination legislation and in some State Disability Services legislation. For example, the *Commonwealth Disability Strategy* recognises that the Commonwealth has an impact on the lives of people with disabilities through its many programs, services and facilities. The Strategy is about enabling full participation of people with disabilities. Under the Strategy, Commonwealth organisations are obligated to remove barriers that prevent people with disabilities from having access to these policies, programs and services. The Strategy is based on the broad principles of equity, inclusion, participation, access and accountability. Jurisdictions that have developed Disability Action Plans include the Commonwealth, Western Australia, Queensland and South Australia.

In some jurisdictions disability agencies have taken a key role in fostering the development of Disability Action Plans within other government agencies in an effort to strengthen access to generic services by people with a disability and to improve interdepartmental linkages. For example in Western Australia, legislation requires that State Government agencies and local governments develop and implement disability service plans. Disability Service Plans are lodged with the Disability Services Commission and annual implementation reports are required.

Practice Example 1: Disability Services Queensland Strategic Plan 2001-2005

The first of eight strategic directions contained within the Disability Services Queensland Strategic Plan 2001-2005 relates to the area of strengthening individuals, families and communities. The plan says: ... "One of the major sources of support and assistance for many people with a disability continues to be their families and informal support networks. For those families and networks that are able to continue to provide such support, this strategic direction works to build and strengthen these relationships and allow families and others to maintain their parental, sibling or friend relationships with people with a disability." Goals of this strategic direction are listed as:

- People with a disability line meaningful and inclusive lives within their neighbourhoods and communities.
- People with a disability have strong families and support networks.
- Communities are inclusive of people with a disability and their families.

Strategies to achieve these goals are:

- "Support the development of flexible responses to people in their local communities which enable them to access informal and formal support.
- Promote opportunities for people to participate in everyday life.
- Increase the number of people with a disability who control their support services.
- Assist families and support networks in their roles as carers and supporters of people with a disability.
- Support families and individuals to access relevant, timely and appropriate information.
- Support families and individuals to network with other individuals and families to identify innovative solutions.
- Support the development of local leadership, skills and knowledge of people with a disability, their families and the communities in which they live".

Source: Disability Services Queensland Strategic Plan 2001-2005, available at www.disability.qld.gov.au

NEEDS ASSESSMENT

Needs based planning is a common approach to service delivery within CSDA jurisdictions and other human service sectors. Queensland, Victoria and the Northern Territory have all developed a statewide needs register for people seeking access to a range of supports provided by government or non-government agencies.

In Victoria, the register operates regionally through an *Intake, Access and Response Team* within the Department of Human Services and is linked to statewide vacancy coordination for urgent applications. Operating since 1997, this process utilises regionally based panels to ensure that access to services is based on relative need. Panel representation is drawn from consumer and/or advocacy groups, regional service providers and departmental representatives.

In New South Wales, the *Service Access System* is a statewide register of people seeking support whose independence or current community support arrangements are at risk and who have been unable to access alternative resources or support from existing providers. Eligible people are referred to support planners to develop a plan to identify the types of support that would alleviate the risk factors for the individual and their carers. Supports are very flexible and can include in-home support, personal care, behaviour intervention, in-home respite, out of home support such as transport assistance, therapy, community access, respite and accommodation support. This system is supported by a population needs-based planning methodology.

Practice Example 2: Intake and Response Services, Victoria

The Department of Human Services in Victoria has developed *Intake and Response Services* (IRS) to replace existing service access systems and to manage the *Service Needs Register* and *State-wide Vacancy Co-ordination*. Key functions of the IRS include:

- Individualised responses to assist people with a disability and their carers to navigate and access community supports and services (eg a contact point for people requiring information or assistance; screening of requests for access to specialist services; determination of eligibility; information provision about disability related issues, supports and services; referral to community supports and services; management of Service Needs Register applications; and a response defined as short term, time limited, task focussed intervention based on the initial needs assessment and risk assessment).
- Systemic responses to create a visible, single point of contact, identify unmet need and inform service planning (eg community education; facilitating partnerships with local generic and specialist services; maintaining accurate local information on supports and services; and assisting in identifying unmet need. People with high, urgent or complex needs may be referred on to case management teams).

The Service Needs Register records stated needs for people seeking a range of accommodation support and day activity programs. All applicants to either government or non-government services are to be registered through the IRS. The Vacancy Coordination process has been developed to ensure that access to accommodation and day programs for people with a disability, within either the government or non-government sector, is based on relative need. Each DHS Region convenes a Regional Priority Panel that includes representation from consumer/advocacy groups, regional service providers and the Department to consider applications for inclusion on the 'urgent' component of the Register. Regions are responsible for maintaining the Register, managing a selection process that matches applications against program vacancies, and for planning new services.

Source: DHS (2001) Intake and Response Service Practice Model and Guidelines, DisAbility Services Division

POPULATION BASED PLANNING MECHANISMS

Population based planning broadly seeks to predict needs and plan earlier intervention. It can assist in monitoring identified need and demand for service as well as a mechanism to decentralise decisions, allowing for community-based response. Population based planning can also encourage help seeking behaviour when individuals are directed to self-help and low intensive services, while waiting for assessment or access to more intensive services.

Practice Example 3: Population Group Planning, NSW

The NSW Department of Ageing, Disability & Home Care (DADHC) uses a Population Group Planning (PGP) methodology to match resource allocation to service demand. PGP quantifies the service needs of a population irrespective of the program or programs through which those services are delivered. The collaborative nature of PGP is underpinned by a Memorandum of Understanding on Joint Planning for Older People, People with Disabilities and their respective carers, between DADHC, the NSW Health Department and the Commonwealth Departments of Health and Ageing, Veterans' Affairs and Family and Community Services.

PGP looks at three populations within disability services:

- Residential Care Population – people living in hostels, institutions and group homes as part of the historical devolution of services.
- Younger People with Disabilities – people with a disability less than 65 years of age. Data is based on the 1998 Australian Bureau of Statistic's Disability and Carer's Survey (next due in 2003). This provides Synthetic Estimates for PGP. Variable co-efficients for this group are levels of disability (Mild/ Moderate/ Profound), Aboriginal and Torres Strait Islander status, rurality (population remoteness) and single parent families as the socio-economic indicator.
- People 65 years of age and over - variable co-efficients for this group are living alone or with others, ATSI and rurality. ABS census data is used as the socio-economic indicator.

PGP indicates the number of service hours being received by each population and the contributions of the respective agencies. PGP provides a decision making tool through a comparative assessment of population data and geographic areas. Qualitative analysis through DADHC's Regional Planning Framework has complemented the quantitative analysis of PGP.

Collectively this analysis has been used to inform the allocation of growth funds targeted to building the capacity of the service system. The analysis has also assisted in specifying improvements to the existing service system such as the need for coordination between services, better use of resources through shared facilities and/or improved care coordination and has enabled DADHC to feed into 'whole of government' initiatives including planning for human services.

Source: NSW Survey Response, Department of Ageing, Disability and Home Care

COORDINATION

The need for improved service coordination in Australian disability services has long been recognised (E-Qal and Donovan, 2000; Fine, 1994). Overseas it is also recognised as an area of challenge (see for example UK Department of Health, 2001). Too often there is a diverse range of programs for people with disabilities with specific eligibility requirements that are fragmented and confusing.

Improving coordination has the potential to increase cost-effectiveness, improve consumer outcomes, generate local responses to need and enhance service delivery. Research also suggests that for families with one or more children who have a disability, coordination can be particularly important at key times in the life cycle, such as entering or leaving school (Cooper et al, 2001).

Examples of some relevant aspects of coordination are discussed on the following pages:

Information Services

Information services can provide a central point of contact for individuals and families to gain access to information, but this must be balanced against the negative consequences of adding yet another layer to an already complicated service system which families must navigate. This is particularly true if families seek complex assistance from multiple service organisations and must undergo eligibility assessments and orientation with each (Fine, 1997).

Practice Example 4: Carelink Centres, Commonwealth

Commonwealth Carelink Centre shopfronts have been established in 54 regions around Australia, operated by a wide range of organisations, including community based, religious, charitable, private, local and state Government. In addition to shopfronts, Centres can be contacted nationally through a freecall 1800 telephone network.

Carelink Centres act as a single point of contact, providing information and guidance about community care services and aged care homes available in the local community. The Centres assist older Australians with their choice to remain living independently in their own home. Commonwealth Carelink Centres can provide information to older Australians, their families, carers, general practitioners, other health professionals or anyone else who needs this information.

The regional focus enables each Centre to develop an awareness of the entire range of services available, to establish networks with local providers and ensure information is up to date.

Source: Information available on the Department of Health and Aged Care website (www.health.gov.au*)*

Multi-Disciplinary Teams

Multi-disciplinary teams can be effective in assessment and referral (where an objective, public, multi-disciplinary approach is taken to screening applicants for care) and in service provision. When used as a screening mechanism, an effective pattern of coordination across the field of long-term care has resulted. Weakness in the model can include the incapacity to ensure that applicants receive the services to which they have been referred (as the administration of resources is usually outside their domain) (Fine, 1997).

Practice Example 5: Community Support Teams, NSW

A Community Support Team is a multi disciplinary team generally comprised of professionals (such as Speech Therapists, Physiotherapists and Occupational Therapists, Social Workers, Community Nurses, Psychologists, Community Workers and Programmers) who provide a range of support services to clients, families and carers. Support services include both direct intervention and the planning and coordination of services provided to a client and his/her family or carer. Services include assessment, case planning and management, counselling, referral, therapy, family support, early intervention and behaviour management. Teams are structured to provide services on either a geographical (e.g. LGA) or client age (e.g. early intervention, school aged or adult) basis. Geographically based teams are usually rural and age based teams are usually metropolitan.

Services are provided through three main activities; intake, case management and direct intervention. Interventions are time limited, data based and regularly reviewed. They include diagnostic assessment, behaviour intervention and support, counselling & family support, skills development, movement and mobility, facilitation of community and social participation, and assistance in the development of communication skills and self care skills.

Source: NSW Survey Response, Department of Ageing, Disability and Home Care

Practice Example 6: Aged Care Assessment Services, Commonwealth

Aged Care Assessment Services have been established across Australia to assist individuals to obtain a range of Commonwealth funded services including home-based supports and more intensive services such as a nursing home or hostel accommodation. Assessment services, usually based at a hospital or community centre, are multi-disciplinary and might include a doctor, nurse, social worker occupational therapist or physiotherapist.

For people living at home, the major services include Home and Community Care (HACC) and Community Aged Care Packages (CACPs). Between 1985/86 and 1995/96, expenditure on HACC services expressed as a share of total recurrent aged care expenditure increased from 15% to 22%, reflecting the shift away from funding for supported accommodation. CACPs provide an intensive level of home care with the aim of enabling people (even those with more complex care needs) to remain at home. Between 1993 and 1998, the number of people receiving a Community Aged Care Package increased from 211 to 8,831. Also reflective of the change in emphasis from the more intensive forms of residential care, hostels increased their share of total aged care expenditure between 1985/86 and 1995/96.

By increasing access and the coordination of home and community based supports the Aged Care program has successfully changed the pattern of service delivery. The number of people entering residential facilities is declining and the age of entry is increasing.

Source: Department of Health and Ageing; the Australian Bureau of Statistics (1999) Australian Social Trends and Gray (2001) Two-year Review of Aged Care Reforms.

Case Management and Service Brokerage

Experience in Australia and overseas has shown that a case management approach (including individual planning and resource allocation) is of benefit to a significant group of service users. The approach is relatively easy to introduce but in some cases can add to cost of services; others risks may include entrenchment of biases and shortages in the service delivery system (Fine, 1997).

Practice Example 7: Local Area Coordination, Western Australia

Local Area Coordination (LAC) is funded and administered by the WA Disability Service Commission. It evolved from a desire to improve service delivery, particularly in non-metropolitan areas. LAC began with a pilot in 1988 and was subsequently implemented on a statewide basis in 2000. It involves a network of Local Area Coordinators (who live in the geographic area in which they work) arranging access to funding and services for people with a disability.

LAC aims to keep families and people with disabilities together and to strengthen communities. It is committed to goals of self-sufficiency, competency, control, choice and quality of life, encouraging and maintaining informal support networks and decreasing dependence on formal supports. It has both individual and community focus, with part of the role of Coordinators being to expand the range of local services and to assist individuals with disabilities and their families to monitor their quality, quantity and appropriateness. LAC assists local people to take control of the required resources and supports the development of informal networks and connections such that individually or collectively local people can engage in advocacy and collaborative activities with other service areas such as education, health and child and family wellbeing. The Coordinator also works as an enabler and provider of information for community groups to assist them establish needed services.

LAC combines a highly individualised support planning and provision process with service and community development. It recognises the customer as the 'expert' when it comes to identifying their own needs and solutions, seeks to provide maximum choice and control over support arrangements and ensure that people have opportunities to pursue their chosen lifestyle. It is the gateway to the state-government administered CSDA funding programs.

Source: Lewis et al (1991) & Disability Services Commission (1998 & 2001).

Packages of Care

Packages of care are an arrangement in which assistance that would normally be provided by a number of separate services is brought together as a 'package' and made available to eligible consumers.

Practice Example 8: Community Aged Care Packages, Commonwealth

Community Aged Care Packages (CACP) are a key element in ensuring that staying at home rather than entering residential care is a real option for those older Australians who choose to do so. To receive a CACP, older people must be assessed as eligible by an Aged Care Assessment Service. Although the program targets older people in the community who have complex care needs, younger people with a disability can also receive a CACP if their care needs fit the criteria and there are no other appropriate services in their area (less than 1% of recipients are aged under 50 years).

CACPs are funded at a level equivalent to the lowest level of personal care in a hostel setting. Commonwealth targets seek to increase the use of CACPs and decrease the use of residential care. CACPs offer an integrated package of services for frail older people and are popular as they are based on a single point of contact for people assessed as needing a range of services. In 1996 clients received assistance such as home help (78%), laundry (67%), case management (67%), emotional support and supervision (57%) and shopping (50%). At least one third were receiving assistance with bathing or showering (48%), meals assistance (42%), delivered meals (40%) and transport (39%). There is a direct relationship between levels of dependency and levels of service provision.

Approximately 3% of CACP recipients are Aboriginal or Torres Strait Islander; this group are typically younger that the general recipient population. Flexible funding is also provided under the Aboriginal and Torres Strait Islander Aged Care Strategy for CACPs delivered through Multi-Purpose Services.

Approximately 25% of CACP recipients are from a non-English speaking background. Capital cities accounted for 62% of CACPs with the average number per service outlet also higher in metropolitan areas. Service outlets are operated by the charitable and religious sector (77%), state and local governments (17%), the private sector (6%) and ex-service organisations (1%).

Data Sources: Information available on the Department of Health and Aged Care website (www.health.gov.au) *and the following reports: Community Aged Care Packages. How Do They Compare (AIHW, 1997) and Community Aged Care Packages in Australia 1999-00: A Statistical Overview (AIHW, 2001b).*

Practice Example 9: Extended Aged Care at Home Pilot, Commonwealth

The EACH pilot program was established by the Commonwealth in 1993-94 to test the feasibility and cost effectiveness of providing care in a person's own home at the level provided in a high care residential facility. The pilot reflects a policy response to community pressure for more care for older people to be provided in the home rather than in institutions. The pilot was first announced in the 1993-94 Federal Budget and trialed in one service. Subsequent approval was given in the 1995-96 Budget for an expanded pilot to proceed. The current three-year pilot extends from 1 July 1998 to 30 June 2001 with ten projects located in NSW, Victoria, WA, SA and the ACT, providing a total of 299 EACH packages (places).

EACH provides an individually tailored package of care and services, depending on the assessed needs of the client. Ongoing monitoring and review of care needs is an integral component of the package. To be eligible, clients must be assessed as requiring high level residential care (nursing home care) and express a preference for receiving care in their own home. An evaluation of the pilot will be conducted to inform decisions about the future of the program.

The pilot program is cost-neutral to the Commonwealth. An EACH place does not become operational until an existing high care place has been closed by the service provider. The rate of subsidy is equivalent to the basic subsidy rate (in the State or Territory in which the project operates) for an RCS category 3 care recipient.

Source: Information available on the Department of Health and Aged Care website (www.health.gov.au)

‘Coordinated Care’

Coordinated Care was developed by the Council of Australian Governments (COAG) to replace over 60 different programs in health and community services with just three streams of care: General Care, Acute Care and Coordinated Care.

The Commonwealth has conducted one round of Coordinated Care Trials and a second round commenced in early 2001 to run for three years. Second round trials will promote enhanced collaboration between the range of individuals and organisations responsible for delivering services to people with complex care needs, particularly where there may be benefits associated with a more organised approach to prevention, early intervention and treatment.

Practice Example 10: Aboriginal and Torres Strait Islander Coordinated Care Trials

Four Aboriginal and Torres Strait Islander Coordinated Care Trials were conducted across five sites in three States and Territories (NT, NSW, WA). Pooled funds were used to provide individual care on a case-by-case basis and to implement community health initiatives. The principal aim of the trials were to test alternative financing arrangements and through this, improve the quality of care for those with a diverse range of health care needs. The trials incorporate matching services to need, funds pooling across multiple agencies and capacity building at an organisational, community and individual level. A distinguishing feature was the focus on empowerment and health system reform to achieve an improvement in the health status of indigenous communities.

The model of care coordination varied across the trials, incorporating different approaches to assessment, care planning and individual case management. Trial experiences suggest that full and comprehensive need assessment may not be necessary and/or appropriate for all clients. A selective and targeted approach may be more beneficial.

Individual supports included access to primary clinical care, care planning, attendant care, illness preventative measures or health maintenance programs. In addition to a focus on individual clients, trials also developed a range of population wide health measures such as health promotion in areas of nutrition, reducing injuries, safe food handling in the home and organised approaches to managing specific diseases such as diabetes, reducing youth suicide and improving social determinants of health. The trials led to greater understanding of the importance of community empowerment as a means of driving health service reform.

Outcomes identified in the evaluation included enhanced service access, with the financial flexibility provided through funds pooling and MBS/PBS funding enabling trials to either develop or purchase new services and develop population health initiatives for their communities; and improved service appropriateness with each trial making a significant investment in the development and implementation of care coordination infrastructure and processes. The trial also confirmed that funds pooling provided an effective mechanism for allocating funding for historical services to community based health service organisations while maintaining flexibility in the way funds could be used.

The extent to which outcomes were achieved varied according to local context. Factors such as geographic isolation, conditional funds pooling, limited investment in local decision-making capacity, limited service options, workforce shortages and limited infrastructure tended to inhibit progress.

This approach requires continued investment in infrastructure support, information systems development, staff recruitment and training. The benefits of care coordination cannot be realised through implementation in isolation but rather through incorporation and integration within pre-existing systems and rely on building the capacity of organisations and the local community. Workforce development is also a necessary component of broader implementation.

Source: KPMG Consulting (2001) Aboriginal and Torres Strait Islander Coordinated Care Trials National Evaluation Summary

CRISIS RESPONSE

Faced with an increasing number of ageing carers and issues of family breakdown, Australian jurisdictions have developed a variety of mechanisms to respond to crisis situations. Many of these initiatives have as their core, the goal of devising assistance that will prevent full-time out-of-home placement, but plans for such placement may also be included.

In Queensland, *Emergency Response Services* funding is allocated annually to non-government organisations within particular regions. Self and professional referrals are made to the organisation when an urgent situation arises for families or individuals.

Tasmania manages crisis response through programs such as *Short Term Support* which provides short term individual support services to clients in their own homes or in a range of community settings and *Service Coordination* which has responsibility of assisting people to gain access to services they need.

In the NT, *Brokerage Funding* is used to prevent an imminent crisis from occurring and thereby diverting the need for more formal intensive supports had the individual or family remained unsupported.

Practice Example 11: Crisis Management, Mental Health Services UK

Building Bridges provides a foundation for the provision of mental health services in Britain. Among initiatives called for are meeting carers' needs for support, periods of respite care, 24-hour access to an emergency mental health service, out-of-hours support such as all-day access to health professionals, a crisis help line, non-medical crisis beds and home treatment services.

The Crisis Management Team at Aintree in the UK was developed in response to these needs with the aim of reducing hospital admissions and forced removal of people experiencing an acute episode. The Crisis Team have a preventative approach, seeking to identify the client at early stages of illness and, within a psychosocial model, using people's own skills to help them to cope. Increasing people's coping strategies reduces the need for future interventions. Teams provide 24-hr help from Registered Mental Health Nurses and Support Workers, with home visits between 9am-midnight and telephone support from midnight-9am. Referrals are accepted from any member of the multidisciplinary team that undertakes pro-active outreach to identify and work with people with high needs. Intervention strategies include the use of respite facilities, as well as added social support.

The Gatehouse Assessment Centre is an acute psychiatric facility that provides assessment and treatment from 9am to 9pm, seven days per week. The centre has a multi-professional team including nurses, social workers, occupational therapists and medical staff, complemented by an outreach worker and a support worker. It has the capacity to provide a rapid response to referrals so that most clients are seen, assessed and start their treatment on the same day. Gatehouse's aim is to reduce hospital admissions and provide an alternative, effective method of treatment for people experiencing acute mental health issues. It has proven effective as an early intervention and prevention approach, leading to the closure of an acute hospital ward within six months and attracting a group of people not known to the psychiatric service that would otherwise have not received assistance until experiencing a crisis. Nurses at the Centre have substantial autonomy, undertaking provisional assessment and developing care plans without the need for the direct involvement of a psychiatrist in the majority of cases. By providing centre based and outreach services as an alternative to hospital admission the Centre has supported people to maintain their family and community links and their regular environment.

Source: *Crompton N (1997) Early Intervention Begins at Home, Nursing Times, Vol 93 No. 52 December 24 1997. Smith C, Price P, Abraham L (1997) The Difference Day-Care Makes, Nursing Times, Vol 93 No. 52*

Practice Example 12: Front Door Services in SAAP, Victoria

Victoria has undertaken a comprehensive review of assessment and referral in the Supported Accommodation and Assistance Program and will be implementing improved assessment and referral mechanisms as part of the Victorian Homelessness Strategy. They are moving to a regional safety net approach based on clearly identifiable 'front doors' to provide clear pathways into the service system.

'Front door' services will conduct an initial assessment to provide sufficient information for the agency to respond immediately to crisis, match the client with available assistance within the service and/or make effective referral(s). The features of a front door service are:

- Accessibility (highly visible and well publicised; telephone & face to face contact; a free call number; walk in capacity with appointments available but not required; staffed working hours at a minimum but with arrangements to provide an extended hours response; a welcoming non-judgemental service culture, and a location close to public transport links),
- Complementary to existing pathways (people can continue to approach any service. If unable to assist they are referred to the front door service together with a preliminary assessment).
- Responsiveness and effectiveness (adequate resourcing for extended hours response; brokerage funds to purchase services; a flexible range of practical assistance options; variety of access mechanisms; and the provision of back up to other parts of the service system eg overnight accommodation for after hours contacts).
- Communication and links (protocols between front door and other homelessness services; protocols with other key services in related services systems; and a clear communication and linkage strategy for state-wide and local arrangements, info and referral mechanisms).
- Linked to the broader service system (access to comprehensive info on service options, vacancies and capacity; access to flexible funds to purchase crisis accommodation and to provide assistance and support until a vacancy in the broader system becomes available; and part time support offered on site or readily accessible eg health care, income support, legal advice, mental health, drug and alcohol, material aid, interpreter services).

Source: Thomas Goodall Associates Pty Ltd (2001) *Statewide Assessment and Referral in Homelessness Services Project*, Victorian Department of Human Services

INDIVIDUALISED FUNDING AND DIRECT PAYMENT APPROACHES

Historically, individual funding developed from a specific accommodation support option and has since been applied across a much broader range of services. Individualised funding models can either allocate funds for a fixed menu of services or they can allocate funds that may be used in a diverse and flexible way to purchase supports. The latter approach appears to be increasingly favoured in the literature, but the former approach is more common in practice.

Individualised funding involves the allocation of funds to a particular service based on service users needs. Individuals within the target group are identified and there is a population-based needs assessment; the funds are then allocated proportionally to each target group based on the relativity of the assessments. There is flexibility for the service provider to apply the resources to the best effect. Reporting is on the overall service, and typically covers the numbers of people receiving the service and the total quantum of services provided.

Individualised funding can be also be 'tied' to an individual, where the allocation of funds is limited to a particular person for a particular service(s). The allocation of that service is preserved for the person and there is an ongoing option for the funds/service to be transferred to another service provider (the principle of portability) if and when that person chooses.

Service providers often manage a number of individually tied funding packages within a given program. The service provider may be granted the flexibility to temporarily reassign resources to manage fluctuations in need across people within a funding program. Reporting is required on an individual basis.

Direct Funding approaches to providing individualised services are growing in popularity. These approaches allocate the resources to the consumer either as a direct payment to the individual who purchases service/supports, or as payments made to services on behalf of the individual by a brokerage agency.

Such approaches are credited with providing greater individual self-determination, choice and flexibility. They are also considered to hold potential cost savings via reduced administration costs and the encouragement of informal care arrangements (instead of professional services). There has been considerable support for these approaches from consumer advocacy groups, however some caution has also been expressed in relation to the way they are implemented (i.e. the method must ensure that principles underpinning approaches are appropriate and that adequate protection is in place).

Practice Example 13: Direct Payments, UK

The Community Care (Direct Payments) Act 1996 gives local authorities the power to make cash payments for community care direct to individuals who need services. Day-to-day control of the money and care package passes to the person who has the strongest incentive to ensure that it is spent properly on the necessary services, and who is best placed to judge how to match available resources to needs.

Any person assessed as 'eligible' for community care services is able to participate. The appropriateness of Direct Payments is a decision to be made on a case-by-case basis (some people such as those subject to mental health or criminal justice orders are excluded). Under the scheme, Direct Payments can be made for any community care service except permanent residential care (including nursing home care). The local authority must ensure that an effective support scheme operates at the local level - designed in consultation with consumers. Support services may be made available either through providing such services directly or in partnership with voluntary organisations. Supports may include single point of contact for advice and assistance, advocacy, referral, peer support networks. Payments cannot be used to pay for services from a close relative.

Direct payments are able to bring about improvements in the quality of life of people who would like to manage their own support. They promote independence and aid social inclusion by offering opportunities for rehabilitation, education, leisure and employment for people in need of care.

Policy guidelines direct Local Authorities to only make direct payments when they are at least as cost-effective as the services it would otherwise arrange, with consideration to long-term best value. A preventative strategy may require higher investment to achieve long-term benefits and savings, for example: direct payments that allow a person to remain in their own home may represent long-term savings if that person does not require hospital or residential care. Although no prescriptive rules are provided, policy guidelines direct Local Authorities to consider the following when establishing a scheme: how to include people with different kinds of impairment, people from different ethnic backgrounds and people of different ages; being creative with the provision of direct payments for both intensive packages and lower level services; about long and short term provision and about how direct payments can be assimilated into preventive and rehabilitative strategies; and consider appropriate monitoring to ensure the adequacy and quality of services purchased for each individual.

Source: United Kingdom Department of Health Publications: Policy and Guidelines White Paper (2001).

Family Support

GENERIC FAMILY SUPPORT

Increasingly family supports are being provided or coordinated through holistic programs that seek to address the needs of the entire family. In Australia, all State and Territory jurisdictions have introduced some level of support specifically targeted at supporting families and increasing their capacity to provide for a member with a disability as well as developing informal and community supports around the family.

Practice Example 14: Families First, NSW

Families First is a coordinated strategy sponsored by the NSW Government to increase the effectiveness of early intervention and prevention services in helping families raise healthy, well-adjusted children. The government departments involved are NSW Cabinet Office, NSW Health, NSW Department of Community Services, Department of Ageing, Disability and Home Care, Department of Education & Training and Department of Housing. The strategy involves a commitment of $54.2m over four years to 2003, by which time it will be implemented across NSW.

The broad aim of Families First is to support parents and carers raising children and help them solve problems early before they become entrenched through a coordinated network of services. The program has four areas of focus:

- Children - to help children to grow to their full potential.
- Parents – to support parents in enhancing their parenting skills and having a sense of control over their lives.
- Communities - to help communities build and sustain networks which will support and connect families.
- The service network - to improve family's access to support through developing a better coordinated service network based on common service delivery principles and a cooperative approach to planning.

The Families First strategy is built on the premise that there needs to be a mixture of universal and targeted services. It is targeted at families with children in 0-8 years age range. The strategy is being rolled out progressively across the state, with six areas already functioning, another five in the planning phase and the balance of areas to be included by 2003. Each area is responsible for funding local initiatives and a key feature is home visiting as a core component of universal early childhood services. Other initiatives include extensions to the "Schools as Communities" projects (a major role of these services is reducing the impact of disadvantage on children entering school by providing integrated services for families in disadvantaged communities), "Parents as Teachers" projects, and funding family workers and Family Support services, supported playgroups and young parents projects.

Families First is based on research which shows that early intervention services can produce sustained improvements in children's health, education and welfare and that early intervention programs that are designed to reduce the risk of child neglect have an important role to play in long term crime prevention. A variety of research projects and resource materials are being commissioned as part of the strategy. These include research on parent education and activities in NSW and a survey of Early Intervention and "Communities 4 Kids"- guidelines for strengthening connections between families and communities. The Cabinet Office is establishing a Research Unit to gather, house and analyse information about Families First.

Source: The Families First Resource Kit, www.parenting.nsw.gov.au

Practice Example 15: Strengthening Families, Victoria

The Strengthening Families Initiative (SFI) funded by the Victorian Department of Human Services (DHS) began in July 1998. Fifteen community service organisations deliver services across Victoria.

The purpose of the SFI is to provide support for families, children and young people who have welfare concerns. It has three aims: to enhance family functioning; to improve family connectedness; and to reduce the intervention of Child Protection in the families' lives. It is not intended to respond to families with children or young people who are at risk of significant harm as defined in the *Children and Young Persons Act 1989*. It is an alternative framework for services to adopt to reduce the need for, and extent of, intervention by Child Protection by adopting a strengths-based approach to achieve positive outcomes for families and encourage hard-to-reach families to receive services.

SFI is targeted at families with children and adolescents aged between 0-18 years who have one or more risk factors (eg history of abuse; violence, substance abuse, poverty, isolation, children or adolescents with conduct disorders, challenging behaviours, school refusal). Families are referred to the SFI services either by Child Protection, community service organisations, or through self-referral. Priority is given to certain families according to a hierarchy of risk factors. There is a high degree of overall satisfaction among families and workers with the needs assessment process used by SFI. The approach of SFI is to reframe the presenting child welfare problems and, in conjunction with the family, identify and address the underlying problems associated with overall family management, family relationships and family resources.

The SFI model comprises four components: assertive outreach, case management, in-home support, and purchasing other services (brokerage) to help families. Brokerage funds may be used to purchase a range of goods and services for families eg utility bills, rental arrears, whitegoods, car repairs, childcare, recreation, school camps, tutoring. There is a focus on family goal-setting and family self-determination in establishing working agreements. There is a high level of supervision, teamwork, staff development and staff support and an embedded culture of reflection and value placed on family feedback. The SFI creates links between services (eg schools, maternal and child health services, hospitals, family support and counselling, domestic violence services, alcohol and drug agencies, mental health services, pre-schools and kindergartens).

The evaluation established that there was clear progress in families in relation to issues of child behaviour and school attendance, consistent with the strong focus on setting goals and providing interventions related to increasing parenting skills within SFI services. The outcomes achieved for families using SFI were established as very positive, using a range of measures such as goal attainment and client satisfaction survey responses, worker satisfaction survey responses and worker and family perceptions of outcomes achieved as a result of the intervention.

Source: Evaluation of the Strengthening Families Initiative, Department of Human Services

FLEXIBLE AND INTENSIVE FAMILY SUPPORT

Flexible Family Support Programs provide small amounts of funding (typically up to $5,000) to address needs such as equipment or technology, housing modifications, support and home help and may also be used to coordinate other services/supports. These programs may be within or in conjunction with more intensive family support programs. Key features of the approach can include that the funding is flexible, can be used to meet needs as defined by the family (with some varying levels of approval restrictions) and that the family can decide how the funds are to be used.

Intensive Family Support Programs provide packages of supports and services for families including appropriate coordination, counselling and advice. These programs have developed from early intervention approaches to supporting children with a disability and their families, in addition to growing knowledge regarding what factors build the resilience of families providing long term care.

Practice Example 16: Family Support Program, QLD

The Queensland Family Support Program (FSP) provides flexible and responsive support to families with complex needs who support a child/children with a disability. These supports are designed to strengthen the families' ability to care for their child as well as to assist families to continue in their caring role. The program provides supports to the child with a disability as well as the whole family. Family support assists families along a sliding scale of a continuum of need from families whose needs are not being met by the current service system to families in crisis who have actively sought to place their child outside the family home.

The program aims to strengthen the capacity of individual families to meet the day-to-day challenge of caring for their child with a disability, to increase inclusion of children with disabilities and their families in the mainstream of community life and to decrease the need to respond to crises and the incidence of requests for out of home care. The program achieves these aims through building formal and informal supports around families that meet the needs and priorities of family members and increase the capacity of families to maintain the care for their child, and by developing best practices in working collaboratively and in partnership with families.

Families generally self-refer - applications are received and entered onto a central database. As funding becomes available further information is sought from families and considered regionally by a priority panel against the available funding. Panels are made up of parents of a child with a disability, family support service provider's representatives and Disability Services Queensland representatives. Applicants are screened on basic eligibility, and allocated to support bands by the panel; then applicants are prioritised against key criteria within each support band. Eligibility requirements limit access to families with children aged 0-18 years who have a disability as defined under the Queensland Disability Services Act 1992 and who are living with their birth or adoptive family.

A facilitator works with the whole family to identify their needs, to assist the family to better access the formal service system and to develop informal networks within community and existing family networks. The facilitator, in conjunction with the family, develops a support plan based around the individual families' needs. FSP also provides access to discretionary funding for the purchase of supports or services. Currently a maximum level or benchmark of funding is allocated according to an assessed level of need but the level of discretionary funds accessed varies depending on the level of need.

There are three levels of recurrent support available, plus one-off or short-term support (allocation into levels of support is dependent on self reported need and key indicators of risk):

- High – the family has a combination of critical issues that require intense and sustained support.
- Medium – the family is not at risk of breakdown, however they have high support needs that require continual support.
- Low – the family is not at risk of breakdown, but requires regular assistance to manage on a day-to-day basis.
- One-off or short-term support – the family manages well on a day-to-day basis but a small amount of one off support would make a significant difference.

In an internal audit of the program in 2000, families reported a high level of satisfaction with the flexibility of the program, the role of the facilitator, involvement in decision-making and access to funding. An external evaluation of the program is currently being finalised. Quantitative data has indicated that there is a high level of satisfaction with current supports and service provision; that families feel that the program has provided increased flexibility in planning, increased flexibility in the use of funds and greater autonomy in decision making; and that the program has enhanced the capacity of families to support children with disabilities to be raised in the family environment.

Source: Survey Response (conducted as part of this research project), Disability Services Queensland, 2002.

Practice Example 17: The Family Care Pilot Program, Wisconsin USA

The US State of Wisconsin has reduced out-of-home placement requests for children with a disability through a comprehensive range of Family Support Programs. A substantial statewide program is the *Family Care Pilot Program*, that provides home and community based services to all people eligible for long term care, which includes older people and people with disabilities. The Family Care Pilot Program seeks to simplify and streamline access to intensive family supports and long-term care. The pre-existing service system was diverse with more than 40 state and locally funded programs with varying eligibility requirements providing a flexible range of services. The Pilot has the potential to transform care management by controlling costs, facilitating consumer-direction, and increasing integration in acute and primary care needs as well as social needs.

The Pilot established two agencies in each local area: *Care Management Organisations* (CMOs) and *Resource Centres* (RCs). The CMOs undertake a comprehensive interdisciplinary assessment of consumer needs and preferences to develop a plan of care. CMO's use a network of local providers to put together care plans, they monitor the quality, effectiveness and changing needs of clients over time. CMO's are funded per person assisted. The Resource Centres provide assistance and information to people seeking long term care (older people, people with a disability etc) including one-stop-shop access to local services and providers, counselling regarding long term care options and information on funding or income-support etc. Assistance is provided by telephone or home visits. RCs are funded on a set grant model.

The Pilot has been thoroughly evaluated. Outcomes reported included improvement in consumer ability to make informed choices and better identification of service gaps, unmet needs and opportunities to improve access to supports through service development or expansion. The evaluation found evidence of innovative practice in distributing information about the services available - particularly the use of technology.

Operating in conjunction with the Family Care Pilot Program is the *Family Support Program* that allocates small grants (up to $3,000) for a broad range of services for families of children with severe disabilities. The state is authorised to approve additional funds to families upon the request of the local administering agency.

The Family Support Program lists 15 specific categories of services a family can receive: 1) architectural modifications to the home; 2) child care; 3) counselling and therapeutic resources; 4) dental and medical care not otherwise covered; 5) specialized diagnosis and evaluation; 6) specialized nutrition and clothing; 7) specialized equipment and supplies; 8) homemaker services; 9) in-home nursing and attendant care; 10) home training and parent courses; 11) recreation and alternative activities; 12) respite care; 13) transportation; 14) specialized utility costs; and 15) vehicle modification.

The program provides support services and also helps coordinate other services a family receives. According to documents describing the Family Support Program, "an important role for the family support coordinator or case manager is to act as a kind of service broker assisting the family through the bureaucratic maze of available programs and services. The worker can also act as an advocate in helping the family to make maximum use of community services, such as community recreation programs, medical and dental services, public transportation, and other generic service providers."

Source: Alecxih L M B, Lutzky S, Linkins K, Zeruld S, Neill C The Lewin Group (2000) Wisconsin Family Care Implementation Process Evaluation Report: Prepared For The Wisconsin Legislative Audit Bureau, USA, available from: Http://www.Legis.State.Wi.Us/Lab/Reports/00-0famcare.Pdf

Practice Example 18: Making A Difference Program, Victoria

The Victorian Making A Difference Program (MADP) provides individualised funding packages that incorporate case management and financial resources to support families caring for a family member with a disability in the family home. Initially piloted in 1992 for families with a disabled member under the age of 18 years, it has now expanded to statewide coverage and includes people aged 18-64. Non-government providers are funded to deliver MADP through the Department of Human Services.

The program goals include strengthening the capacities of families to care for their family member with a disability at home. The program assists families to develop a care plan that will meet their needs and is based on informed choices. It aims to maintain existing care arrangements and prevent out of home placement.

The target group includes people with acquired brain injury, physical, sensory, intellectual and neurological disabilities, aged 5-64 as identified in *the Intellectually Disabled Persons' Services (IDPS) Act 1986* or *the Disability Services Act 1991*. Priority is to those who have complex needs or whose needs are subject to rapid change, are experiencing significant difficulties in accessing community services and need flexible service responses, where the family is at risk of breaking down, or where people have special needs because of ethnic/aboriginal background or geographic isolation or ageing carers.

MADP providers and clients/families work collaboratively to access a range of primary care and community services and build informal support networks in the community. Short-term assistance packages (minimum of 20% of total program funding), intensive support packages (maximum of 80% of total program funding) and discretionary targeting is available. In addition, DHS Regional Offices have discretion to vary the mix of package types allocated to MADP providers.

Individualised funding can be used to top up existing services, establish a new service, recruit a pool of sessional workers/volunteers, assist with holiday program or camp participation, hold information forums/ parent support groups, provide short-term loan of equipment or purchase non-PADP equipment. Services that can be purchased are very flexible and could include vehicle and home modifications or household items (e.g. washing machine, drier).

Sources: DHS (2000) The Making a Difference Program Guidelines, DisAbility Services Division

SHORT TERM (RESPITE) CARE

Short-term care has been identified as one of the most important services in giving carers a break, with priority to service models that provide culturally normative and inclusive developmental, leisure and socialisation opportunities for children and young people with disabilities (Cooper et al, 2001).

Short-term care programs operate in all jurisdictions across all client life stages and are seen as strengthening the support arrangements that operate within the family. Across Australia, the large unmet need for residential accommodation puts pressure on respite services - three in five families were reported to be waiting for additional respite services.

Research suggests that flexible respite is of particular importance to families. A service system must be able to provide both regular planned respite and also be responsive at short notice when unpredictable needs arise (Intellectual Disability Services Council, 1998). Additionally, short-term care needs to be provided as part of a coordinated, integrated package of support for families, rather than as a single type of support provided only on an emergency basis (Baldwin & Carlisle 1994*)*. Contemporary short-term care programs are also moving away from traditional overnight respite in centre-based facilities to providing a mix of options in a variety of settings.

Practice Example 19: Lifespan Respite, USA

In the USA, Oklahoma, Oregon, Nebraska and Wisconsin have implemented a program called Lifespan Respite. Lifespan Respite is a coordinated system of accessible, community-based respite care services for caregivers and individuals regardless of age, race, ethnicity, special need or situation. Respite care is planned or emergency short-term relief to caregivers from the demands of ongoing care for an individual with special needs or at risk of abuse or neglect. Special needs may include any disability, any chronic or terminal physical, emotional, cognitive or mental health condition requiring ongoing care and supervision, including Alzheimer's disease and related disorders, developmental disabilities, children with special medical needs, and any other condition determined by the state. Crisis respite may also be used to provide a temporary safe haven for the care recipient in the event of an emergency brought on by domestic violence, substance abuse, or a housing, health or job crisis.

Nebraska's Lifespan Respite Program was implemented in 2000 by the Nebraska Department of Health and Human Services to coordinate respite care services for people with disabilities. The program is broken into six community-based programs, each serving as a single contact point for consumers who need access to respite care. During the next two years, each program will assess the specific needs of the community it serves and determine if enough providers exist to handle the need; they will then conduct marketing targeted toward families, providers and businesses to increase awareness of the program's existence and the benefits of respite care. Each program will then recruit more providers as required and develop and administer training programs for caregivers, whether they are professional service providers or families.

In Oklahoma the program also plans to develop training for mainstream child care services to improve access for children with a disability.

Source: US National Respite Coalition web site information and comparison of programs (http://www.chtop.com/NRC-Lifespan.htm)*; and Fox-Grange W; Folkemer D, Burwell B Horahan K (2001) Promising Practices Issue Brief: Community-Based Long-Term Care, Forum for State Health Policy Leadership. National Conference of State Legislatures, USA.*

EARLY CHILDHOOD INTERVENTION

Early intervention, intensive family support and specific behavioural intervention strategies are all important responses to mitigate problems of challenging behaviour and its potential to precipitate out of home placement.

Early intervention programs for children with a disability typically operate from birth until school age. There are a large number of services available (over 500 services in NSW alone) operated by a range of providers.

Practice Example 20: Early Childhood Intervention Coordination Program, NSW

The Early Childhood Intervention Coordination Program involves the NSW Ageing and Disability Department, the NSW Department of Community Services, the NSW Department of Education and Training and NSW Health in association with non-government organisations.

Governed by a State-wide Committee, Area Committees and Local Committees, the Program facilitates communication between families, service providers and policy makers to enable coordination of early childhood intervention services. The coordinated approach seeks to achieve early identification of children and families who need support, provide information to families about available services, ensure that quality services are provided and provide a mechanism for planning services to meet the needs of the child and family.

The program has developed a Manual and Training Package entitled 'Recommended Practices in Family Centred Early Childhood Intervention'. It has also established an 'Infoline' to access a database of over 500 early intervention services in NSW, provided education programs to families and services, and facilitated shared resources between services.

Source: Early Childhood Intervention Coordination Program Brochure

PARENT EDUCATION AND EMPOWERMENT

Listen To Us, a project conducted by the School of Social Work and Social Policy at La Trobe University (Cooper et al, 2001) identifies as a priority the need for parenting skills education and resource materials to be available to parents of children with disabilities as part of parenting skills education available to all families.

Families need information to understand the cause, nature and implications of their child's disability in order to set reasonable expectations for the future and to begin to regain some control over their lives (Roberts 1986). Families should also have access to locally relevant information and support where required, to assist them to navigate the services system and coordinate the services they require (Cooper et al, 2001).

Practice Example 21: Components of Family Support Programs, NSW

Types of programs that can assist parents include discussion groups and education programs, child-parent activities and crisis intervention counselling. Some specific examples from family support programs in operation in NSW include:

- Enjoy Being a Parent course (Parramatta Holroyd Family Service).
- A fathers group, Beyond Beer and the Barbecue (Parramatta Holroyd Family Service).
- Fresh Start recovery seminar for people separated and divorced (Lower Mountains Family Support).
- Mid-Week Club for children aged 5 to 10, with dinner at a fast food outlet, then drama focussing on healthy ways to express emotions (Armidale Family Support Service).
- A women's group, Keeping Children Safe (Armidale Family Support Service).
- Assertiveness course including protective behaviours (Moree Family and Adolescent Support).
- Sole parent group and an ADD parent support group (Naomi Family Program).
- Ideas for parents course; Facing the Challenge - Fathering in the 90's (Cowra Family Support).

Source: Gledhill M (1996) Family Resource Programs, Strengthening families and communities, Children Australia, Vol. 21 No. 4

HOME-BASED SUPPORT

A variety of home-based support options operate across the different life cycle stages. For example, Attendant Care, Home and Community Care and Home Nursing provide practical assistance to maintain people with a disability in their own home - typically, these services are available to individuals and families across a broad age range based on needs assessment, eligibility and priority guidelines. (Services may be subject to means testing and available on a user-pays basis).

A number of jurisdictions also operate outreach and drop in support to provide additional assistance to maintain a person with a disability in their own home. This may include personal care, skills building, behaviour intervention and assistance with the skills of daily living.

In some programs care may be 'packaged'. For example in South Australia, irrespective of client life stage, support packages are provided to families through *Options Coordination* to ensure family integrity and prevent residential placement.

Practice Example 22: Options Coordination, South Australia

Options Co-ordination provides a single point of entry to the disability services system through five lead Options Coordination Agencies (OCA) based on disability types (Intellectual, Adults with Physical & Neurological conditions, Brain Injury, Children with Physical & Neurological conditions and Sensory). Developed in 1994/95, Options Coordination combines case management, community development and service brokerage. Options Coordination is designed to provide individualised supports to people living in the community to maintain and enhance quality of life.

OCAs determine access and plan services around individuals using a standardised process that is client focused and aims to give clients a choice of response, service delivery model and provider. It has six stages: assessment; support planning; matching support plan(s) and appropriate providers; attaching notional resources to support plans; contracting; and monitoring.

Access is limited to clients under the age of 65 (existing clients can continue to receive support beyond their 65th birthday) and people living in their own home (i.e. not residing in grant funded or aged care supported accommodation). Eligibility, priority of access and support needs category determinations are made by the Options Co-ordinator in accordance with relevant guidelines. The support needs category is a score assigned to the client from a scale that forms part of the Needs Assessment Report.

Once a client has been assessed the Co-ordinator considers the informal supports available to the client and works in partnership with the client (parent/carers) to develop an appropriate support package. An OCA may have clients who are receiving a financial package only or receiving case management only or awaiting an allocation of a package subject to availability of resources. Brokerage funds are provided for a range of supports including personal care, equipment and respite services.

Recent reviews have made a number of recommendations to improve consumer outcomes and service effectiveness. The success or failure of the process depends in part upon the attitudes and functioning of individual Coordinators, including strong local knowledge and experience. (It was suggested that consideration be given to also allowing people to go directly to local services). It was also suggested that consideration be given to consumer managed packages and 'cash in' opportunities while endorsing that the case management components within the Options Planning Process constitutes a legitimate service response for some clients. Other recommendations for improving the application of this approach included more consistency in the application of the options planning process and needs assessment through consistent standards for Coordinators, consistent reporting requirements and consideration to team audits across the five agencies, and the development of a coordinated approach to the monitoring of demand, prioritisation and state-wide service planning/development.

A review of support packages has recommended a framework for setting support package parameters against each of levels in the scale of need, with the maximum level to which brokerage funds should be allocated set at $80,000 (the equivalent of a group home placement for people with high support needs with +10% variance for country regions). Issues have been identified with regard to setting rates with providers, as there are wide variations in costs of similar services across areas and client groups.

Source: Committee on the Evaluation of Quality Services for People with Disabilities, South Australia (2000) Options Coordination Policy Statements (Various) (1997-2000).

FINANCIAL SUPPORT

Yuan et al (1996) found that some families use flexible funds from disability support systems for more basic needs such as utilities, clothing and food. McLeod et al (1997), evaluating Victoria’s Early Choices Program, comments on the fact that in some instances it was more helpful to families that the program pay their ordinary household bills while the families themselves met specific costs related to disability themselves. (Such approaches would need to be aware of potential issues relating to any interface with generic financial relief programs).

Practice Example 23: Stronger Families Strategy (Financial Assistance Component)

The Commonwealth Department of Family and Community Services (FaCS) Stronger Families Strategy represents a commitment to strengthening families as a fundamental unit in society. This commitment is delivered through a combination of services and family-based approaches to income support, with an emphasis on government, community and family partnership. The strategy brings together income and child support payments, support services and other assistance available to families, children, young people and students. Other assistance includes family relationships support, parent education to prevent child abuse, and services for families in transition or need.

Financial assistance to families is provided in various ways. Most notable for families of children with disabilities are the Carer Payment for people with full-time caring responsibilities (constant care for a child less than 16 years with profound disabilities) and the Carer Allowances (Child) for people with significant caring responsibilities for one or more children with less severe disabilities. The Carer Allowance (Child) replaced the previous Child Disability Allowance in July 1999.

Source: Department of Family and Community Services, description by Cooper et al (2001)

BEHAVIOUR INTERVENTION

The presence of challenging behaviour involving aggression can have a substantial impact on individual and family wellbeing. If challenging behaviour is not addressed it can lead to reduced access to education and services, increased family caregiving responsibilities and family stress and may begin a cycle of family violence. International studies suggest that approximately 10-20% of children with intellectual disability will present with aggressive behaviour. The prevalence of challenging behaviour amongst people with intellectual disability appears to increase markedly in late adolescence before diminishing in mid-adulthood. Males are more likely to be identified as having challenging behaviour and rates typically increase in accordance with intellectual impairment (Adams & Allen, 2001).

Positive approaches to behaviour management, including pro-active behaviour change strategies (eg environmental and antecedent manipulation, skills building and reinforcement-based approaches) have proven highly effective in modifying challenging behaviour including aggression. Families may need training in safe and effective strategies for responding to aggression when it occurs while longer-term preventative strategies are put into place (Adams & Allen, 2001).

Practice Example 24: Stepping Stones, WA

'Stepping Stones' builds on Triple P - the Positive Parenting Program of family intervention for children who have, or risk developing, behaviour problems. Based on clinical research it provides structured strategies (through a variety of 'Tip Sheets') for promoting children's competencies and parenting competence and confidence. Designed for children from birth to twelve - or pre adolescence - it addresses social and language skills, emotional skills, independence skills and problem solving skills in children and parenting skills directed at developing positive relationships, encouraging desirable behaviour and teaching children new skills and behaviour.

The program targets preschool children aged from 2-6 years with a six-month intervention phase and 12 month follow up. Program evaluation indicates a range of positive outcomes including increase in parent competence in managing common behaviour problems and developmental issues found among children with disabilities; reduced parent use of coercive and punitive methods of disciplining children; improved parent personal coping skills and reduced stress; and improved parent communication.

Source: Disability Services Commission, WA date unknown Stepping Stones: Practitioners Manual

Practice Example 25: Signposts for Building Better Behaviours, Victoria

Signposts for Building Better Behaviours is a comprehensive set of materials for parents and a supporting set of manuals for workers, developed through the Intellectual Disability Parent Support Project to help families who have school-aged children with intellectual disability and difficult behaviour. The project involved extensive research with families to identify strategies used to manage the behaviours and factors which impact on coping strategies. The most commonly used strategies include asking the child to stop and ignoring the behaviour, whereas the least commonly used strategies were getting physical help and administering medication. Parents often relied on their immediate systems of support such as partners, extended family and friends, for help such as advice, support or practical assistance.

Parents perceived that the most useful help available was in the form of practical assistance provided by a range of services and/or individuals. While parents used teachers as sources of help the most, they rated help provided by early childhood intervention services as more useful and regular respite care was rated the most significantly useful of all sources of help.

Having a supportive partner, understanding child development, understanding behaviour as a form of communication, having siblings or peers to act as models for appropriate behaviours, planning ahead and being able to deal effectively with service providers were also factors that helped parents deal effectively with challenging behaviour. Lack of appropriate respite care, or long term residential care, parents own feelings, separated families, trying to balance the needs of all siblings, inappropriate peer models, difficulties with services providers and difficulty in accessing services, all made it more difficult to manage challenging behaviour.

The parent materials developed included eight information booklets, a video that shows examples of the strategies in the booklets, and a workbook in which parents can practice working out appropriate strategies. Parents can use the material independently, with telephone support or by attending a series of six group sessions.

The worker materials are provided in three manuals. The manuals will assist the workers to provide support to families who are working through this program and will also help the workers to monitor how helpful the program is to families. Workers also attend training sessions and are supervised by senior workers in their region.

Testing the materials with a variety of parents and workers has shown that they are useful, parents who used the materials reported that they felt more confident, less stressed and were experiencing fewer hassles in their parenting role. The parent's also reported that their children's behaviour was less disruptive and less anti social. Families who received the materials with the support of a worker (either telephone support or attending a group) were more likely to complete the program than families using the materials on their own.

Source: Cameron C (2001) Signposts for Building Better Behaviour Summary of Project Outcomes available from: www.vicparenting.com.au/projects/disability.htm

SUBSTITUTE CARE

Disability Programs are developing a range of approaches to meeting the needs of children who require out of home placement due to a breakdown in family coping or assessed risk and the need for child protection. As an alternative to residential care, host family or substitute care models are being developed. Better coordination or cross-program collaboration with child protection substitute care programs is also assisting to produce better outcomes.

Practice Example 26: Alternative / Host Family Model, Northern Territory

The Alternative/ Host Family Model seeks to prevent the entry of children with disabilities into the State care under the Family and Children's Services Program. Many parents of children with disabilities are voluntarily surrendering care of their children but are doing so without the safe guards and case management provided by the substitute care system. The aim of the model is to ensure that the family remains in control of the decision making in respect of the child and linkages between parents and child are kept intact. The target group is families with children 0 to 18 years who are unable to continue caring for their child full time and who are seeking alternative care. Where possible, families are involved in the selection and identification of the alternative/host carer. Carers would be assessed (by a non-government agency) for care of the particular child and the family would provide respite to the carer.

Historically children with a disability requiring alternative care have been placed in either in residential settings managed by non-government organisations or live with foster parents where the placement is managed by the Family and Children's Services Program. Some children with high support needs residing in residential settings have also been the clients the Family and Children's Services program. Substantial efforts have been made to find alternative arrangements that avoid the necessity of entry into 'care' however identifying people who are willing to provide alternate care is difficult.

Source: Cooper et al (2001)

TRANSITION TO ADULTHOOD

Services provided to school age children include those identified in previous sections (eg respite care, behaviour intervention) and specific programs that operate within or abutting the school system (this project did not examine education supports). Services at this stage in the life cycle predominantly aim to support families and provide children with skills for adulthood and facilitating access to education. There is some evidence that informal support networks reduce in size as the child becomes a teenager or as behaviour problems arise. As support drops, parents may become more reliant on formal support from services, possibly exacerbating any problems.

"When young people with disabilities leave public school, their entitlement to special education and related services ends. They - and their families - leave behind a relatively organised service provider system and become solely responsible for identifying, pursuing, obtaining, and coordinating the educational training and services needed for them to prepare for employment and independent living" (NICHCY, 1996).

Across Australian jurisdictions, increasing recognition has been paid to the need for programs to bridge the transition from school to adult life, particularly for those people with a disability who have not been able to access appropriate employment services immediately following completion of their schooling.

Practice Example 27: Future for Young Adults, Victoria

Futures for Young Adults is an individualised funding program designed to assist school leavers with disabilities in their transition from school to an adult day service option of their choice. Options include existing services such as University, employment, recreation through to specialist disability services such as day training centres, TAFE, specialist employment services and leisure options. The program involves individualised planning and service purchasing. Funding is portable and can be transferred from agency to agency as the needs of the young person change. A program evaluation has found that the program was well regarded by participants, with each young person obtaining the post school option of their choice. The portability of funding was highly regarded and the evaluation highlighted the need for participation of the young person in assessment and planning processes, and for regular review and monitoring.

Source: Victorian response to AIHW Research Project Survey, 2002

Independent Living

This section examines some current and emerging approaches to assisting adults with a disability to live independently in the community. (Residential care and high support accommodation models such as group homes are excluded from this review).

For the purposes of this review, we define independent living programs to be based on an individual and flexible approach to long term care, working closely with the individual to provide assistance in arranging and managing both formal and informal supports. A broad interpretation is taken: for example, included are funding models that allow for greater consumer management (including direct payment to the individual) in purchasing independent living supports.

INFORMAL SUPPORTS

The Australian *National Study of Disability, Ageing And Carers* reports that over 90 percent of adults with a disability live in private dwellings in the community either with partners, family members or alone (ABS, 1998). It has been estimated that roughly half (49 percent) the population of people with a disability living in the community receive informal assistance from family friends or neighbours, while 27 percent receive formal assistance from services (ABS, 1998).

Formal supports provided to people living in the community can increase individual independence, provide practical assistance that reduces the need for informal supports and expand the opportunities available to people with a disability with regard to social or economic participation (eg community access, employment options). They can also be targeted to work alongside informal carers to support their role, in recognition of the needs of family carers who provide lifelong care.

HOME-BASED CARE - POPULATION BASED PROGRAMS

The European Forum (1999) provides the following OECD definition of long-term care "*any form of care provided consistently over an extended period of time, with no predetermined finishing date, to a person with a long-standing limiting condition or who is at risk of neglect or injury*". Long-term care contains at least four kinds of help or support: skilled medical and nursing care, personal care, domestic support and social support.

Long-term care provided in community settings (either in a family context or alone) is generally referred to as home-based care and seeks to enable people to live independently, preventing or delaying the need for facility based care. A common approach to providing home-based care for older people and people with a disability are broad population based programs such as the Home & Community Care (HACC) program.

The National Ageing Research Institute & Bundoora Extended Care Centre, (1999) describes the rationale for HACC as the provision of services that aim to achieve modest outcomes for larger groups rather than more substantial outcomes for smaller groups. While the needs of these larger groups are diverse they can be mostly addressed by common and general kinds of interventions that provide basic support.

Practice Example 28: Home and Community Care, Commonwealth

The Home and Community Care (HACC) program is a central element of the Federal government's aged care policy, providing community care services to frail aged and younger people with disabilities, and their carers. HACC currently funds a wide range of State and Local Government agencies and non-profit organisations; revised agreements have removed the restriction on commercial services. In 1999 there were approximately 4,000 HACC-funded organisations, providing services to about 275,000 people at any given time, or approximately 540,000 people per year.

The aim of the HACC program is to enhance the independence of people and avoid their premature or inappropriate admission to long-term residential care. The type of services funded through HACC include community nursing, paramedical services, meals on wheels and day centre-based meals, home help, personal care, home modification and maintenance, transport, respite care, education and/or training for service providers and consumers, assessment and/or referral services, information and advocacy services, and social and carer support. HACC does not provide support in areas of activity that lie outside the designated service types, eg income support, housing, pharmaceuticals, recreation or employment services. Some HACC services are provided through Community Options Projects (COPs or Linkages) that involve case management for higher need clients.

The operational definition of the HACC target population translates into those with a need for assistance and individuals are eligible to receive services in the areas of activity with which they require assistance. The need for one or other service does not qualify an individual to receive all other services eg a consumer may be eligible for home help but not personal care. Eligibility and priority is determined at the service provider level in accordance with broad guidelines. Providers have flexibility in their approach to assessment and access provisions, allowing some local adaptation.

Source: Information available on the Commonwealth Department of Health and Aged Care website (www.health.gov.au)

HOME-BASED CARE - CONSUMER-DIRECTED PROGRAMS

Increasingly, consumer-directed programs that provide long-term care for elderly persons and people with a disability are being developed and implemented at national or jurisdiction level (consumer directed models are currently operating in all Australian jurisdictions). These approaches enable the consumer to identify their support needs, develop a care plan, and manage their care arrangements including hiring, training and supervising home care workers.

Such programs may replace or complement population based approaches. Where the two approaches co-exist, population based programs typically provide low levels of care to a broad population, while consumer-directed approaches provide access to higher levels of care based on stricter access and eligibility requirements.

Consumer directed programs are typically managed by state, county or local government agencies that provide beneficiaries with a cash payment meant to either buy services or support informal caregivers or with a "voucher" to purchase services from an independent worker.

An issue relating to consumer-directed programs is whether quality of care is adequate and how services should be monitored to ensure consumer safety - particularly for people with cognitive impairment who may be vulnerable to abuse. Limited quantitative research and interviews with stakeholders suggest that at least client satisfaction, if not quality of care, with consumer-directed services is comparable to agency-directed care and may be higher (Tilly et al, 2000).

Practice Example 29: Cash and Counselling, USA

The Cash and Counselling Demonstration and Evaluation is being conducted in three States (Arkansas, Florida and New Jersey), funded by the US Department of Health and Human Services and the Robert Wood Johnson Foundation. The program began in 1995 with background research and establishment occurring until 1998 when the first consumers were enrolled in Arkansas. It is anticipated that 7,000 consumers will participate in the trial and cash subsidies have been guaranteed to individuals for a period of two years.

The expected outcomes of the trial include greater client autonomy and consumer satisfaction; increased flexibility in the type and range of supports available to consumers and cost reduction resulting from reduced administrative expenses as a result of cashing out benefits.

The three demonstration States are offering the cash option to elders and adults with disabilities; children with disabilities are also included in one State (Florida). Consumers receive a cash benefit and choose who provides personal and essential services (help with bathing, eating, dressing, etc), as well as when and how they are provided. For example, in Arkansas, *Independent Choices* gives beneficiaries who are eligible for Medicaid personal assistance services (PAS) the option to receive a monthly cash allowance in lieu of traditional services. Beneficiaries may use the allowance to hire caregivers or purchase equipment that would enhance their ability to live independently. In addition to the monthly allowance, the demonstration provides counselling services (for example, to help the client develop an allowance expenditure plan) and bookkeeping services (for example, to pay and withhold taxes for caregivers hired with the allowance). Clients who are unable to manage their own PAS may have a representative (eg family member or legal guardian) do it for them.

The demonstration is being comprehensively evaluated using a control group receiving traditional services. The evaluation will examine: participation rates and characteristics of consumers choosing this option; consumers' service utilisation and preferences; the quality of care; service costs and issues related to paid and informal workers; how the cash option was implemented in each state and identification of environmental factors that can explain program effects; how the cash option team (consumer/representative, worker, and counsellor) work together; whether any outcomes worsen (eg appropriateness of amounts allocated and availability of supports, vulnerability to abuse or neglect); the experience of caregivers who are hired and paid under the demonstration (eg working conditions, job satisfaction etc); the impact on informal carers (eg decrease/increase stress); and effects on public costs (eg increase/decrease in service costs, level of provision etc).

A preliminary review of 197 people participating in the Arkansas program found that more than 80% of participants felt their quality of life was improved, while none claimed it was diminished. Further, 95% were satisfied with the time of day they had assistance. 78% of the "employees" were family members. Demonstrated outcomes include high satisfaction among consumers and evidence of cost neutrality to government.

Sources: Foster et al (2000); University of Maryland (2001); The Home and Community-Based Services Resource Network (2001) Fox-Grage et al (2001)

Practice Example 30: Personal Budgets for Long-Term Care, Netherlands

In The Netherlands personal budgets have been introduced for people in need of care for extended periods (more than three months). The main objectives are to support informal care giving and to improve choice for individuals.

Those who receive a personal budget have to become a member of the Social Insurance Bank that takes care of the administrative tasks like paying salaries to carers employed by personal budget holders. The amount of payment is based on the assessment of hours of care needs and the tariffs for the different kinds of services. From this amount a means-tested co-payment is deducted.

Personal budgets are first of all used to buy services from for profit and non-profit providers and the so-called alpha-helpers employed by care receivers as informal providers. Alpha-helpers are a centrally coordinated workforce of carers that can be employed to work with people in the home.

Source: European Forum (1999) Beyond the Health Care State: Institutional Innovations and New Priorities in Access, Coverage ad Provision of Health Services. Florence 26-27 February 1999, Conference paper WS/32

SUPPORTED LIVING

The 'supported living' model is a consumer-directed approach (similar to those described above) to providing high levels of support to people with a disability and particularly people with an intellectual disability. O'Brien (1993) defines supported living as "*a person with a disability who requires long term, publicly funded, organised assistance allies with an agency whose role is to arrange or provide whatever assistance is necessary for the person to live in a decent and secure home of the person's own*". He goes on to say that the promise of supported living lies in its potential to deal creatively with the complexities arising from the lives of many individuals.

Australian examples of this approach include the *HomeFirst* program in Victoria and the *Individual Options Program* in Tasmania, although all other States and Territories also operate programs with varying degrees of similarity.

Practice Example 31: HomeFirst, Victoria

The HomeFirst program was launched in October 2000 as a new initiative funded by DisAbility Services to address the support and development needs of people with a cognitive disability (Acquired Brain Injury or Intellectual Disability). It was introduced to provide home and community based supports that assist people to continue to live independently in their own homes and community, or to make the transition from staffed accommodation to independent living arrangements.

HomeFirst provides a flexible range of support and services to facilitate independent living. These may include home and community-based support, essential goods and equipment. Supports include support coordination, personal care, community access, and skills development (eg household management, cooking, decision-making, conflict resolution etc). Support coordination is an important component of this program and is undertaken by a service provider who is separate to the direct support provider. HomeFirst is intended to be part of a range of supports that a person may require and may be receiving. It may provide up to 34hrs per week of support with additional short-term emergency support is available where a person's needs increase temporarily.

A review of the program in 2001 identified the need for amalgamating In Home Accommodation Support and Accommodation Outreach programs to provide greater flexibility and support for individuals, in recognition that needs change over time and program boundaries were restricting the effectiveness of the programs.

Source: DHS (2001) HomeFirst Guidelines, DisAbility Services Division

Practice Example 32: Individual Options Program, Tasmania

The Individual Options Program aims to assist people with disabilities to live in the least restrictive environment in the community, exercise greater independence and control over their lives, and increase their participation in the activities of the community. This is achieved by the provision of support that is usually to a maximum of 34 hours per week (resource provision at these levels can usually not be sustained by other programs). This support may include personal support, respite or day options, supports with activities of daily living in the home or community; routine, non-specialised maintenance of adaptive equipment and/or other non-specialised personal care and related tasks.

Applicants must be under 65 years of age on entry to the program, have a disability as defined by the Disability Services Act (1992), be able to personally direct support workers regarding their support needs or be able to use an advocate to do so, require support and not be receiving compensation for continuing care or be a ward of the state. Applications are assessed by a Referral Committee based on a statewide waiting list. Priority is based on consideration of a range of risk factors to individuals and carers. Supports may be purchased from a range of approved service providers (based on Disability Service Standards) or individuals may hire workers directly.

Individuals are involved in the day-to-day management of their support system/program including the selection/direction of workers, the design of the support system, involvement in the monitoring of services, negotiating contracts of services with a service provider and regular reviews of the arrangements in place. Contracts of service are developed with each provider detailing agreed supports with regard to nature, level, frequency etc. An individual may choose to change providers but must provide written notice with an appropriate timeframe for the transfer of payment.

The Individual Options Program is targeted to people living with ageing or long-term carers and people in rural areas, however a similar 'Personal Support Program' is available to other target groups in Tasmania.

Source: Survey Response and Individual Options Program Guidelines, Disability Services, Tasmania.

TRANSITIONAL PROGRAMS

Transition to independent living is a significant time in any individual's life - it is a 'window of opportunity' for developing the life skills required to maintain and increase independence, autonomy and resilience over the life cycle.

Individual supported living models generally acknowledge and seek to respond to changing needs over the course of an individual's life and have mechanisms for regular review of individual support needs. However, the mix of supports available for purchase by individuals and/or brokers is usually limited to either independent workers hired directly by or on behalf of the individual, or service agencies that provide long-term care. There are few examples of service models that specifically target the transition phase, with the exception of the ACT *Mature Carers Program* (see practice example below) and strategies within the Victorian *HomeFirst* program to support people with a disability leaving residential service settings. Other examples provided below are from outside the disability services sector (specifically, programs that seek to provide intensive supports to young people at-risk of recurring homelessness, long-term unemployment and welfare dependence).

Practice Example 33: Independent Living Support Teams, SAAP Program, SA

Independent Living Support Teams assist and support young people who will need support to access housing, develop skills in household management and adjust to independent living. There are two teams, each with one Senior Youth Worker and three Youth Workers, in the North and South regions of Adelaide. Currently the service is metropolitan only, although it is developing a consultancy role to rural areas. The target group is 15 to 18 year olds who are under the guardianship of the minister, young offenders, or assessed as 'at-risk adolescents' by Family and Community Services.

The service is characterised by a very 'hands on' approach, focused on supporting young people (as opposed to 'doing it for them'). It is concerned with an experiential/practical/ alongside approach to learning. Workers receive training in very practical skills to enable this (eg housing maintenance, choosing electrical goods, moving furniture). It provides a very discrete type of support in independent living (other types of support continue to be provided by social workers).

The process of moving on to independent living typically takes place over six to 18 months. The young person is assessed regarding their readiness to live independently, and their willingness to be involved. Then the teams assist the young person to find housing, first trying to find private housing with bond assistance; however, if this fails, the option of direct lease (trust) is explored. The service assists with providing basic necessities, and setting up with household goods. The final element is skills training, in areas such as budgeting, cooking, hygiene. These activities are individually tailored to each young person and are highly flexible.

Teams may provide three levels of support: twice weekly, weekly, or fortnightly. Outcomes achieved include that 70% of service users remain in independent living for over six months (based on approximately 140 clients per annum). Potential outcomes include a common system/tool for assessing a young person's independent living skills and planned responses; a common curriculum for experiential learning of independent living skills by young people; an increase in the number of young people remaining in independent housing for over six months and an operational manual regarding best practice in the program.

Source: Department of Family and Community Services (2001) 'Sleeping Rough' - Youth Homelessness: Division Youth Services/CRC/MAYT

Practice Example 34: The Foyer Scheme, UK

Originally a model developed for ordinary young people to provide a stepping-stone to adult life, the Foyer Scheme is based on the French model of foyers pour heunes travailleurs (housing for young workers). Foyers were developed in Britain in the early 1990's; by early 1999 there were 78 schemes and the number continues to grow. Foyers or foyer-type projects have also been developed in other European countries, the USA and most recently a number of pilots are being developed in Australia to respond to youth homelessness.

Foyers have evolved into a transitional housing model that provides support in the development of social and life skills for independent living. This includes work on budgeting and home skills such as cooking and shopping. Some provide health care advice, social skills development etc. Approximately 50% include employment training and support - in these services young people living in the foyers must be actively committed to a plan of action for furthering their careers and moving on to more independent housing. They receive employment preparation and training, literacy/numeracy skills development and support for moving in and out of training and work (temporary work and/or multiple job starts).

During the pilot of the scheme in Britain, by the end of 18 months nearly thirds of those who started had left the program with around 25% achieving the 'ideal' outcome of finding a job and moving on to their own independent housing. Others moved into their own accommodation before they had found a job but continued to implement their employment action plan. The model requires agreement on the value of an integrated approach to working with young people and careful consideration to how services can be delivered, including the nature of supports that are most effective in building long-term functional capacity. Evaluations have identified positive outcomes including young people reporting positive experiences, skills development and enhanced self-esteem. However, evaluators also identified the need for more explicit acknowledgment of the structural barriers faced by young people in the labour market and housing system.

Source: Anderson (2001) Housing and Support Services For Young People: Are Foyers An International Model? University of Western Sydney, Urban Frontiers Program, Issues Paper 7

Practice Example 35: Mature Carers Program, ACT

The ACT Mature Carers program provides support to carers and people with disabilities where the carer is aged over 65 years. Support is provided to the carers to enable them to have respite, information about options available to them and plan for the time when they are no longer able to care for the person with a disability in their home.

The person with a disability is provided with support in selecting the most appropriate future care arrangement, gaining the skills they need to be more independent (if possible) and for a service to assess their care needs outside the current arrangement.

Source: *ACT Department of Health and Community Care Disability Priorities, Survey Response*

EQUIPMENT AND ASSISTIVE TECHNOLOGY

Internationally, there is increasing attention on the use of assistive technology to enhance the independence and opportunities of people with a disability. Assistive technology is defined as "*any product, instrument, equipment or technical system used by a disabled person, especially produced or generally available, preventing, compensating, relieving or neutralising the impairment, disability or handicap*" (Price Partnership & IRv, 2000). The most commonly cited benefits of assistive technology are in relation to the development of tools for improving communication, orientation and mobility for persons with sensory, motor and/or cognitive impairments, to empower individuals to participate in society.

The importance of building accessibility to new and emerging technologies has been recognised in some countries and supported by legislation, codes or regulation (eg the USA Telecommunications Accessibility Enhancement Act 1988). It is anticipated that the use of advanced assistive technology will increase, as more technology is adopted in all spheres of life, and that increasingly assistive technology will also be purchased on an individual or private basis.

Most CSDA jurisdictions provide programs that provide funds for purchasing assistive technology (including individual funding and family support models that permit the use of funds for equipment purchases).

Practice Example 36: National Strategy for Assistive Technology, USA

The United States has a national strategy for assistive technology and an array of legislation driving the development and availability of accessible technology in the mainstream market (largely through government support to developers). National and state-based initiatives are in place to increase access for people with a disability to assistive technology, including:

- Increased investment in Assistive Technology Research and Development and improved coordination through increased funding to 15 national Rehabilitative Engineering Research Centres.
- Promotion of Private-Public Partnerships through an "Assistive Technology Development Fund" to help underwrite technology demonstration, testing, validation and market assessment to meet specific needs of small businesses so that they can better serve the needs of people with disabilities.
- Increased access to often prohibitively expensive assistive technology via low-interest loans (grants will go to a state agency in collaboration with banks or non-profit groups to guarantee loans and lower interest rates).

Source: Price Partnership & IRv (Institute for Rehabilitation Research) (2000) Study on Technology Trends and Future Perspectives within Assistive Technologies: Final Report, Report to the European Commission.

EMPLOYMENT PLACEMENT AND TRAINING

In an international review of disability policies and trends for the World Bank, Metts (2000) identified that employment strategies for people with a disability have included quota and levy systems, vocational rehabilitation and state authorised disability-specific enterprises. Though elements of all strategies continue to exist in various forms, vocational rehabilitation has enjoyed the most widespread acceptance and is central to many national disability policies. Models of services in Australia are similar to international jurisdictions and include:

- Open employment services that assist people with a disability to secure employment in an external company or organisation (the open labour market). Typically consumers receive assistance with gaining employment and some initial support to maintain employment but go on to have a normative relationship with their employer earning competitive (award) wages.
- Supported employment services provide employment within the organisation itself. These may be within a large business operation (Business Services) or a smaller group placement model (Small Business, Work Crew or Enclave).
- The Commonwealth Rehabilitation Service assists people with a physical or sensory disability (existing or acquired) to gain or return to work through support with job search, workplace modifications etc.

From a systems perspective access to employment provides greater independence and economic resources for people with a disability, potentially leading to reduced dependence on formal services and reduced reliance on informal carers and families.

Reviews and research in the disability employment support sector in Australia have led to substantial reforms being introduced over the past four years. The reforms include funding linked to individual needs and outcomes, quality assurance and better assessment. These reforms aim to improve opportunities to participate in work, better link funding to support needs and outcomes, and improve the quality of employment outcomes provided for people with disabilities.

Practice Example 37: Case Based Funding Trial, Commonwealth

The Commonwealth is currently trialing a new way of funding disability employment assistance. Funding under the trial is based on a job seeker's assessed need for assistance in finding and keeping a job and employment outcomes achieved. The trial is being undertaken in a variety of regions throughout Australia. Phase One of the trial commenced in November 1999 and the intake of job seekers to this phase of the trial ended in June 2000. Phase Two of the trial commenced in January 2001 and commencements ended June 2001. Phase Two of the trial tests a new funding classification process. The interim evaluation of the trial has been completed and will be released shortly with a final evaluation in August 2002.

Access to disability employment services is based on an independent assessment conducted by Centrelink to stream people into levels of funding based on the Work Ability Tables. Applicants for the Case Based Funding Trial are assessed using the Job Seeker Classification Instrument (JSCI) to determine the job seeker's labour market disadvantages and the Disability Pre-employment Instrument (DPI) to determine their disability related support requirements. The JSCI is completed by Centerlink and the DPI by the employment assistance provider. The instruments together determine the job seekers funding level.

Source: Survey response, Commonwealth Department of Family & Community Services

Practice Example 38: The Ticket to Work Program, USA

The Ticket to Work and Work Incentive Improvement Act represents a significant opportunity for increasing the employment of people with disabilities. The program provides for two landmark measures that have the potential of enabling millions of Americans with disabilities to join the workforce. The first is the creation of the Ticket to Work Program administered by the Social Security Administration (SSA). This program modernises employment-related services offered to Americans with disabilities. Through the Ticket Program, individuals with disabilities will be able to get job-related training and placement assistance from an approved provider of their choice. This provision enables individuals to go to providers whose resources best meet their needs, including going directly to employers. The second measure expands health care coverage so that individuals with disabilities will be able to become employed without fear of losing their health insurance.

Initially the Ticket Program will only be available in certain states. Under the terms of the Act, the program will be available throughout the country by January 1, 2004. Benefit recipients will receive a paper document representing the Ticket and a letter of explanation with instructions and information about the Ticket Program. If the recipient chooses, he or she can take the Ticket to an “Employment Network.” The recipient will receive a list of approved Employment Networks from the SSA and can choose the one whose resources best fit her or his needs. Recipients can also choose not to use the Ticket. This will not affect their disability benefits. A benefit recipient electing not to use the Ticket may still use the services that are otherwise available through state vocational rehabilitation agencies.

The payment structure for employment services is incentive-based and intended to ensure that individuals receive the ongoing services needed to maintain employment and succeed at work. The Act authorises Employment Networks to be paid a percentage of the national average SSI or SSDI benefits under either an outcome payment or outcome milestone payment system. Under the outcome system, the Employment Network will be paid for each month a beneficiary does not receive a benefit check because of work or income for a period not to exceed 60 months. The 60 months need not be consecutive. The milestone system is similar. However, it provides for payments when the beneficiary reaches specified milestones while preparing for, or seeking, permanent employment, at which point the outcome payments begin.

Source: US Department of Labour (2000) Ticket to Work and Work Incentive Improvement Act Factsheet, available from: http://www.dol.gov/dol/odep/public/media/reports/ek00/ticket.htm

HIGH SUPPORT NEEDS

Substantial stress is placed on families when young people with high support needs leave school and are not able to access further education, employment or day programs. Often a parent or carer must stay at home to provide care during the day, reducing the economic and social participation of the parent and potentially the wider family group.

People with support needs at the higher end of the spectrum often require complex, long-term and more costly supports. Improving employment access for people with high support needs has high potential benefit with regard to reducing family care responsibilities for adults living at home. There is also an impact on the day supports provided by adult day programs and home-based support services (accommodation, residential, community access etc).

Practice Example 39: Coordinated Packages of Employment & Day Support

Stability or safety-net support is particularly important for families when any change in the daily routine of a family member with a disability may impact on the workforce participation of other family members because of care requirements. Family preferences for services that offer stability with regard to maintaining daily routines need to be recognised as a legitimate need but should not result in restricting the options for people with a disability who have high support needs. The provision of short-term in-home respite or access to alternative day programs in the event of job loss could improve families' capacity to support people entering open employment.

One approach to addressing this issue are coordinated packages of employment support and day programs, possibly incorporating other supports such as transport or personal care. This was the basis of the REAL Options model proposed in 1995 by a sub-group of the NSW Council of Intellectual Disability - a framework based on zero exclusion and individually tailored supports, incorporating funding from different government sources pooled to purchase a package of supports that might include training, employment, day programs etc. A similar example operates in the US state of Massachusetts which involves coordinated funding arrangements through an agreement across departments that provides for:

- Each relevant government department to fund that component of the individual's support that is their responsibility.
- Agreed reimbursement rates to service providers.
- A standardised paper trail and a single point of contact for all service providers.
- Central coordination by the Department of Vocational Rehabilitation, including distribution of paperwork to each department when it is their responsibility to pay for a component of the client's support (each department then pays the provider directly).

Source: Tuckerman P (2001) How Successfully Are People With A Significant Intellectual Disability Accessing Employment? Paper presented at ACROD Conference November 2001; Options Network (approx. 1995).

If better access to employment can reduce demand for day support programs, conversely, increased availability of day support programs may act to decrease employment participation. In NSW, the Post School Options (PSO) program was established in 1993 because increasing numbers of students with significant support needs were remaining at home. Tuckerman (2001) correlates declining participation in employment with an increase in participation in the PSO for a group of participants. (However, it is recognised that without appropriate day support, extra stress is placed on families and demand for residential services is likely to occur at an earlier stage).

LABOUR MARKET CHANGES

Workforce trends identified by the Australian Employment and Skills Formation Council (ESFC, 1994) included strongest employment growth in high skills jobs and weakest in low-skills jobs, with increasing demand for middle-skills jobs. Workers are increasingly required to be multi-skilled and be able to self-manage. The Council identified negative impact on people with disabilities who historically have a lower skills base, lower rates of participation in higher education and training and more limited employment exposure. The Council also identified that much of the jobs growth is in the small business sector and although this sector has a good record regarding the employment of people with a disability, it also has a much higher rate of separation and job losses.

Global trends (Price Partnership & IRv, 2000) include that short fixed-term contracts will be the norm, having already increased from 9% of all contracts in 1985 to 12% in 1995, and that part-time employment and multiple employment will increase as people become more diverse in the ways they choose and are able to spend their time. 'Portfolio careers' will be more popular for employees who will need to be more flexible in turning their hand to a variety of tasks. People must become more psychologically flexible and geographically mobile.

Home Based Work

Programs and services that support working from home arrangements (either as a contractor or as a telecommuting employee) for people with a disability are receiving considerable attention in the United States, Canada and the United Kingdom. These approaches are sometimes seen as a solution to transport and physical access problems for people with a disability.

Practice Example 40: Work From Home Evaluation, Canada

A small study in Manitoba, Canada, explored the experiences of 21 people with a disability working from home, either full-time or part-time, as employees of a company (i.e. not self employed). Common reasons for working at home were often related to the individual's disability and included:

- They gained the flexibility to work when they felt most productive and rest when necessary.
- Employers' workplaces were physically inaccessible or lacked assistive technology they required.
- Working from home allowed better access to attendant care or pain management strategies that were unavailable or difficult to arrange at their employers' workplaces.
- It allowed them to avoid extreme weather conditions that exacerbated pain related to their disabilities or created risks of falling on slippery winter surfaces.
- Because previous employers had not accommodated them satisfactorily when they disclosed their disabilities and/or requested accommodation.

In addition to the reasons they worked at home, the study participants identified a host of additional benefits and advantages of working at home, including freedom from distractions and office politics, less stressful, reduced time spent travelling to and from work, save money on lunches and work clothing, flexibility to care for sick family members, flexibility to attend to non-work activities (eg. going to bank, doctor), and flexibility to work when the disability would make it difficult to go to employer's workplace.

Source: Canadian Centre on Disability Studies (2002) Best Practices in the Home-Based Employment of People with Disabilities, Manitoba, Canada. Available from: http:/www.disabilitystudies.ca

Self Employment

Many of the difficulties in beginning or operating a small business faced by people with a disability are the same as those encountered by others, but these difficulties can be compounded and become seemingly insurmountable barriers (ESFC, 1994). People with a disability often have a lower financial base from which to start small business, lenders are often more reluctant to provide finance to someone with a disability and the cost of capital equipment may be higher due to the need for adaptation or modification (ESFC, 1994).

Notwithstanding, research indicates a growing interest amongst people with a disability in self-directed employment. International jurisdictions including Canada, the United Kingdom and the United States report a range of initiatives or programs to support or facilitate self-directed employment. However, such programs sometimes experience a low take-up for reasons including:

- Employment advisers reluctant to recommend or encourage self-employment for people with a disability seeing this as an inferior outcome to paid employment within a company, based on assumptions regarding risk for the individual and higher costs associated with supporting a person to establish a business enterprise (Floyd et al, 1998; Metts & Metts, 1998).
- Establishment, support and training costs higher than the norm (Metts & Metts, 1998).
- Mainstream small business support agencies and training providers being unable to cater for people with a disability (Floyd et al, 1998).
- Low levels of awareness amongst people with a disability of the supports available, and lack of networking between disability employment advisers (Floyd et al, 1998).

Practice Example 41: Small Business Self Employment Initiatives, USA

In the US small and micro business is experiencing strong growth and creating a substantial proportion of new employment opportunities. In particular, small businesses are most likely to generate jobs for young workers, older workers and women. The 1990 national census revealed that people with disabilities have a higher rate of self-employment and small business experience (12.2 %) than people without disabilities (7.8 %).

The University of Montana Research and Training Centre on Rural Issues for People with Disabilities has documented that entrepreneurs with disabilities have successfully operated a wide variety of businesses: accounting services, air conditioner repairs, auction service, auto body repair shop, bakery, bicycle shop, childcare service, chiropractic practice, counselling, farming, janitorial/maintenance service, piano refinishing service, real estate office, restaurant, freelance writing, used clothing store, and others.

For these people, self-employment offered many benefits but they also needed to be aware of the challenges involved in starting a business. There remained an array of obstacles ranging from attitudinal barriers to lack of coordination among Federal programs and including:

- The possible loss of cash benefits from SSDI or SSI disability programs.
- The possible loss of health care benefits such as Medicare or Medicaid.
- The inability to get credit because of poor credit ratings.
- The lack of assets to use as collateral.
- The lack of access to programs promoting self-employment and small business development.
- Government disability programs that overlook entrepreneurship as an avenue to self-sufficiency.

The 1999 passage of the Ticket to Work and Work Incentives Improvement Act addresses some, but not all, of these issues. People with a disability may use employment assistance funding (provided through Ticket to Work) to establish a home-based business with support from an employment service. The Office of Disability Employment Policy's new *Small Business Self-Employment Service* (SBSES) provides further information and a variety of other technical assistance resources for writing business plans, financing, and other issues specific to developing a small business. The Office of Disability Employment Policy has also initiated a range of activities with other Federal agencies to ensure that Federal employment programs for people with disabilities will promote small business ownership as a career option, and that potential entrepreneurs with disabilities know about the process and resources for starting a business.

Source: US Office of Disability Employment Policy's web site at www.dol.gov/dol/odep/

ALTERNATIVES TO EMPLOYMENT

The rationale for alternatives to employment may be summarised as: "*Paid employment is not a viable, suitable or a preferred option of all people with a disability. It is therefore essential that meaningful and appropriate day occupations are provided as an alternative to paid employment that fulfil the function of skill enhancement, achievement, community connection and integration into employment. 'Alternatives to employment' is an activity which people choose to participate in within working hours that provides them with valued roles. The aim is to ensure that people with disabilities who require alternatives to paid employment have access to a range of options which encourage involvement in everyday community life whilst providing skills development, enjoyment and/or satisfaction. Alternatives to employment is a service delivery model that challenges providers to be innovative, creative and flexible in meeting client needs*" (Buchanan & King, 1995).

There are 'Alternative to Work' programs operating in all CSDA jurisdictions. These programs have been experiencing increasing demand and have been identified as having high unmet need (AIHW, 1997). Post School Options programs are typically provided for young adults during the years after they leave school to assist transition to either higher education and training, employment or alternative to employment programs and to provide living skills, social networks or recreation supports.

The capacity to provide regular, ongoing service is often an important feature of this approach for people with high support needs. The need for 'guaranteed' service can be a barrier to accessing employment. Increased flexibility could allow for alternatives to employment to provide increased supports while employment options are being developed or during periodic unemployment. Difficulties in moving between employment and non-employment options or to combine employment and non-employment options for an individual even where it may be in their best interests have been identified in a number of reviews (Yeatman, 1996; Buchanan & King, 1995).

SUPPORTING OLDER ADULTS

As identified by Grant (2001b) the definition of 'old age' in people with disabilities is problematic in age-related and functional terms because of varying rates of ageing within subgroups. Bigby et al, 2001 adopt the age of 55 years to define an ‘older person with a disability’. The age of 55 years appears consistent with most published Australian research on ageing and disability and much of the international research (Grant, 2001b). There are parallels with the use of the mid-fifties age for defining eligibility for Aboriginal and Torres Strait Islanders to Commonwealth Aged Care programs due to reduced life expectancy and premature ageing.

Some of the difficulties that older people may experience include *"forming and maintaining personal relationships based on intimacy, affect and reciprocity - often because people are 'retired' from day services or rehoused away from friends, and sometimes because they move away or die; the sense of loss* *following bereavement from lost contact with family, friends or key others can be profound and kept concealed; the difficulties of gaining admission to and acceptance by generic facilities like 'integrated' clubs and societies remind them that their 'differentness' is somehow more than superficial; and occasional taunts from neighbours and young people about their demeanour or dress code can remind them that their citizenship status is yet to be fully accepted by others even if it is rightfully claimed*" Reference.

Practice Example 42: Day Support for Older People With Disabilities

The report *Ensuring Successful Ageing: Report of a National Study of Day Support Service Options for Older Adults with a Disability* conducted by LaTrobe University (Bigby et al, 2001) examined the support needs and best practice responses for older people with a disability. It identified seven broad types of programs utilised by older people with disabilities:

- Specialist aged programs located within age-integrated day, leisure or vocational services for people with disabilities.
- Stand-alone age specialist services specifically funded and designed for older people with disability.
- Initiatives combining a specialist disability service with aged care services.
- Community development projects.
- Brokerage services.
- Centre-based or non-centre-based age integrated leisure or day program with individual planning.
- Residential-based programs with no day support funding.

The report found that no one service type demonstrated a unique or exclusive capacity to excel on all key criteria for effective services. Programs demonstrated variable capacities on criteria of individualised planning and choice, maintenance of social networks and participation in the community. Overall, not all types performed as well with respect to skill maintenance, opportunities for self-expression and sense of self and promotion of health and a healthy lifestyle. States and Territories differ in relation to the extent to which they have begun to develop policy and services for older people with a disability. The following types of community and service development tasks should be explored:

- Promote and support inclusion for older people with disabilities in community leisure programs.
- Recognise resource demands to support access to community facilities.
- Develop strategies and incentives for coordination around individuals between day and accommodation providers (and other providers).
- Cease the practice that people cannot return to their supported accommodation at certain hours.
- Develop protocols regarding access to aged care services.
- Recognise that community development must occur, in addition to individualised funding, to develop initiatives that extend physical and social access and program options to underpin individual approaches.
- Recognise the need for day services, for all age groups, to be more flexible in order to obviate the need for younger people with high support needs to be included in programs for older clients as a way of achieving flexibility.
- Develop the capacity of day support services to respond to changing needs and interests over time.
- Remove barriers to service entry that are based on notions of double dipping and adopt coherent criteria for entry to services based on a coordinated and integrated service system around individuals.

Source: Ensuring Successful Ageing: Report of a National Study of Day Support Service Options for Older Adults with a Disability conducted by LaTrobe University (Bigby et al, 2001)

ABUTTING PROGRAM AREAS

Individuals with a disability and their families use a wide range of services and supports, not all of which are funded through the CSDA. Appropriate links between complementary service systems should be in place to ensure holistic needs can be met. Pertinent abutting programs include:

- Child Care - The Commonwealth Child Care program and State/Territory early childhood education programs provide services to support working parents and provide educational and social opportunities for children. Services include long day care, family day care, out of school hours and vacation care, pre-schools and in-home care for families that cannot access other service types. The representation of children with a disability in childcare services between 1997 and 1999 was lower than their representation in the community in all jurisdictions where the information was available (SCRCSSP, 2001) - 2.3% of children in childcare have a disability compared to 7.6% in the community.

  The Commonwealth funds two complementary programs to help the families of children with additional needs to gain access to child care services (available in services approved for Child Care Benefit). They are the Supplementary Services Program (SUPS) and the Special Needs Subsidy Scheme (SNSS). SUPS sponsors, usually community based services, are funded to employ a network of SUPS workers to provide assistance to child care workers such as training and advice about the care of children with special needs, inclusive programs and planning for these children, specialised resources, information and short-term relief staff. State and Territory jurisdictions have an array of supports available to assist the integration of children with a disability in children's services.

- Home and Community Care **-** The interface with HACC services is crucial as these services fund in-home respite, host family respite and some other activities designed to give carers a break. The need for closer coordination between the disability sector and HACC has been discussed in several other reports (Committee on the Evaluation of Quality Services for People with Disabilities, South Australia, 2000; E-QUAL & Donovan Research, 1997; SCRCSSP, 2001).

- Health Services - Access to health services including domiciliary and nursing care are important services for people with physical disability. Mental health services are important for people with cognitive disability or mental illness.

  The World Health Organisation (2000) identifies that as adults with intellectual disability have more lifestyle choices, they may be exposed to risks not previously anticipated, such as tobacco use, substance abuse, violent behaviour and high-risk sexual activity. Passive lifestyle factors may also pose risks (eg a sedentary lifestyle may lead to obesity). Research in developed countries suggests that adults and older persons with intellectual disabilities have rates of age-related conditions that are comparable to the rates for the general population. Over their life span, adults with intellectual disabilities should maintain the same array of preventative health habits and receive the same protective health services as those offered to the general population.

- Housing - The increasing trend to separate support from housing in human services (across homelessness, aged care, mental health and disability) has created numerous alternative approaches to assist individuals in leasing or purchasing a home. These include the use of trust funds, co-operatives, subsidies and other creative strategies. Opportunities exist and can be created to meet an individual's preferences and circumstances (Hulgin et al, 1996).

  There is particular emphasis in some countries on strategies to encourage and support greater home ownership among people with a disability. The Canada Mortgage and Housing Corporation supports research and information on accessible housing, and financial assistance is made available to landlords and low-income homeowners for home modifications (Government of Canada, 1999). In the USA the Freedom Initiative recently announced by the Federal Government (2001) also includes strategies to promote homeownership for people with disabilities. The American Homeownership and Economic Opportunity Act of 2000 will permit social security recipients eligible for rental assistance and public housing to receive up to a year’s worth of assistance as a lump sum to finance the down payment on a home. The rationale behind this scheme is that mortgage payments, unlike rental payments, help build net worth because a portion of the payment goes toward building equity. In turn, as one’s home equity increases, it becomes easier to finance other purchases such as a computer or further education.

  Inadequate housing can also increase the support needs of people with a disability and in some cases prevent independent community living. For example, an evaluation of housing needs of disabled people who were wheelchair users found that a significant number of disabled people were being made more dependent by their housing (Sapey, 1995). Improving access to appropriate housing and housing modifications can improve the quality of life of people with a disability and reduce demand for formal supports.

- Transport - Inadequate access to transport is a commonly difficulty for adults with a disability living in the community. Solutions to transport difficulties caused by inaccessible or inadequate public transport services include community transport (eg provided through the HACC program), subsidies and tax reductions to allow individuals or families to purchase and modify private vehicles, and transport provided by funded disability services within the context of support delivery. The 1995 review of alternative to employment services in Western Australia found transport has a major influence on programs and that over 70% of service users were reliant on agency/service transport (Buchanan & King, 1995).

  Overcoming barriers to the use of public transport, taxis and transport provided by other community programs (eg health services for medical appointments) has significant potential benefits for people with a disability in relation to social participation and potential cost savings in CSDA-funded programs.

- Aged Care - Access to Aged Care for people with a disability and the integration of supports between service systems is a growing area of focus for disability programs. A number of jurisdictions have adopted the 'ageing in place' principles of the Commonwealth Aged Care Program and are developing strategies to increase coordination between aged care and disability.

  The World Health Organisation (2000) recommends that ageing-supportive social and health policies should be focused on promoting productive or successful ageing for all. It is unrealistic in the context of developing services for older people to split off the emerging population of older people with intellectual disability from the rest. The need is to develop infrastructures for health and ageing which can be accessed by older people with intellectual disabilities. In this way, natural inclusion can be facilitated, supported by relevant training for both professionals and the wider public. Further, specialised resource centres need to be available to allow clinicians, families and carers to seek information, referral and training.

PART 3: ANALYSIS OF APPROACHES

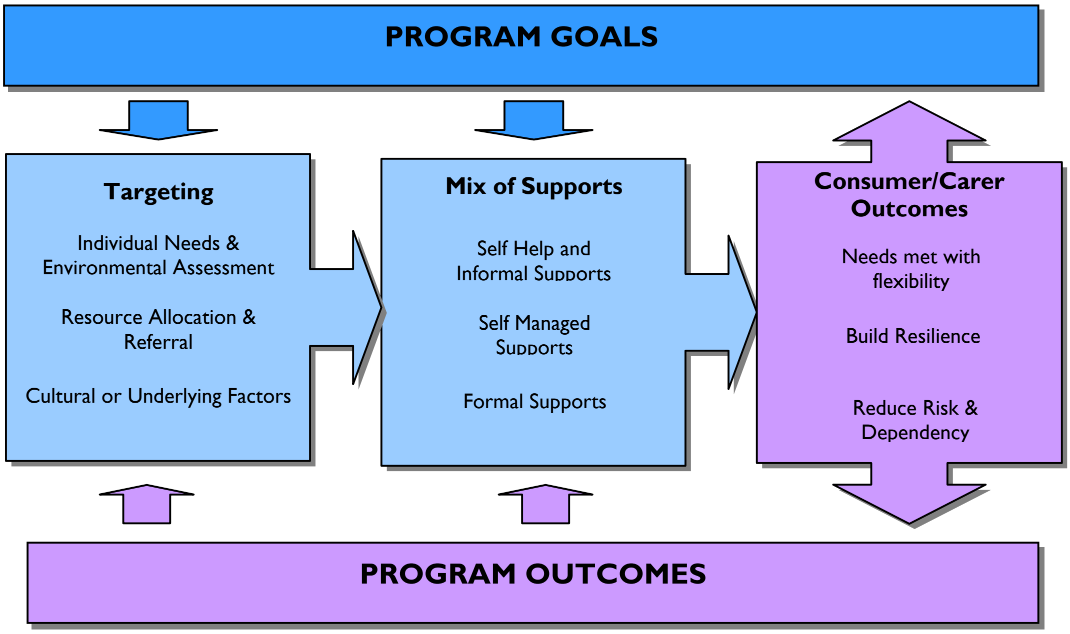
Research to this point in the project has identified a number of approaches with the potential to improve service responses to the needs of families and individuals over the long term. Examples of actual service models (drawn from current disability services and abutting systems both within Australia and overseas, via a literature review and survey of Australian jurisdictions) have been used to illustrate these approaches.

In order to guide and target more detailed analysis of the selected approaches, a 'Framework for Analysis' has been synthesised.

Framework for Analysis

A service system may be thought of in terms of five key components as shown in the diagram below. The relationship between components is dynamic.

Figure 5: Relationships between Framework Components



Practical attempts to better meet service needs and prevent or defer the requirement for more intensive services must work at the operational levels of the system model: Targeting, Mix of Supports and Consumer/Carer Outcomes. For each of these components, a number of principles that contribute to capacity to effectively respond to the needs of individuals and families have been identified - these form a *Framework for Analysis* (see Figure 6 on the next page).

This section of the report examines how services might meet the principles of the Framework and how variations in the application of the approach might impact on outcomes for consumers and program administrators.

Figure 6: Framework Principles

Principles
1. Builds Resilience across the Lifespan
1.1 Adopts a strengths-based approach to building the resources of individuals and families.
1.2 Provides supports and resources in ways that encourage, develop and maintain healthy, stable relationships among family members with focus on early intervention and encouraging help-seeking behaviour.
1.3 Demonstrates a lifespan or long-term perspective, providing support either within or through transition between life stages with clear links to future outcomes.
1.4 Seeks to transfer decision-making power to people with a disability and their families and carers.
1.5 Complements and works alongside informal supports to strengthen informal support networks for families (rather than depending solely on professional support systems).
1.6 Provides information and learning opportunities, including skills development.
2. Impacts on Need and Environmental Factors at Community, Family and Individual Levels
2.1 Encourages 'linked' action across all areas of government activity, improving access to generic as well as specialised services across the diversity of community living eg housing, transport, and employment.
2.2 Takes into account the individual's environment (i.e. recognises the interplay of individual and environment characteristics), including the total family situation and needs.
2.3 Decentralised decision-making provides flexibility and autonomy for workers including opportunities to spend time on inter agency coordination.
2.4 Incorporates a very strong principle of understanding and being guided by the individual or family's lifestyle, values and daily routines and accommodations
2.5 Services are extensive, flexible and provide an individualised range of supports, with timing of interventions to converge and support multiple needs.
3. Increases Efficiency and Effectiveness of Service Provision
3.1 Increases cost effectiveness of service delivery.
3.2 Incorporates elements of training and support for professionals, staff and volunteers involved in the delivery of services.
3.3 Applies referral and assessment tools that are appropriate to the level of need and minimises (where possible) duplication in assessment and eligibility requirements.
3.4 Improves access to under-represented groups including indigenous people, people from culturally and linguistically diverse backgrounds, geographically or socially isolated families and country communities.

Approach 1: Service Coordination

1. Builds Resilience Across the Lifespan	
(1.1) Adopts a strengths-based approach to building the resources of individuals and families.	In Western Australia, Local Area Coordination (LAC) has a charter which reads in part "*to support people with disabilities and their families to identify their own needs, determine their preferred services and control the required resources, to the extent they desire, so that they can pursue their chosen lifestyle*". LAC pursues a strengths-based approach guided by a set of principles and values which revolve around building individual, family and community self-sufficiency. To be effective in promoting a strengths-based approach, the principles and values must permeate all aspects of the program and practices within the program must be reviewed to ensure they are coherent with them. Staff selection, development and training must similarly reflect the principles and values.
(1.2) Provides supports and resources in ways that encourage, develop and maintain healthy, stable relationships among family members with focus on early intervention and encouraging help-seeking behaviour.	A lack of service coordination can lead to increased family stress and may prevent families or individuals contacting services prior to a crisis situation developing. One of the primary benefits of effective coordination is to engage people in the service system early in order to provide preventative support and build resilience. In Western Australia, LAC combines a highly individualised support planning and provision process with service and community development. It recognises the customer as the 'expert' when it comes to identifying their own needs and solutions, seeks to provide maximum choice and control over support arrangements and ensure that people have opportunities to pursue their chosen lifestyle. LAC also has an early intervention function in that it serves as the gateway to state-government administered CSDA funding programs, including Accommodation Support, Flexible and Intensive Family Support, Alternatives to Employment For Adults, Post School Options for School Leavers, Therapy, Aids and Equipment. The Commonwealth's Extended Aged Care at Home pilot program (EACH) aims to preserve 'normal' family relationships by providing a tailored package of services and supports designed to allow a person to continue living in their own home. Without an EACH package, the person would have required full time residential care necessitating a move, often away from partners or their place in another relative's home. In the UK, The Gatehouse Assessment Centre is an acute psychiatric facility that has proven very effective in early intervention and prevention. The Centre provides assessment and treatment from 9am to 9pm, seven days per week, through a multi-professional team including nurses, social workers, occupational therapists and medical staff, complemented by an outreach worker and a support worker. It has the capacity to provide a rapid response to referrals so that most clients are seen, assessed and start their treatment on the same day. By providing centre based and outreach services as an alternative to hospital admission the Centre has supported people to maintain their family and community links and their regular environment.

(1.3) Demonstrates a lifespan or long-term perspective, providing support either within or through transition between life stages with clear links to future outcomes.	The NSW Department of Ageing, Disability & Home Care (DADHC) uses a Population Group Planning (PGP) methodology to match resource allocation to service demand. PGP quantifies the service needs of a population irrespective of the program or programs through which those services are delivered, and irrespective of age cohorts or residential circumstances. PGP indicates the number of service hours being received by each population and the contributions of the respective agencies. Collectively this analysis has been used to inform the allocation of growth funds targeted to building the capacity of the service system. The analysis has also assisted in specifying improvements to the existing service system such as the need for coordination between services, better use of resources through shared facilities and/or improved care coordination and has enabled DADHC to feed into 'whole of government 'initiatives including planning for human services. In Western Australia, LAC works with individuals and families across the life cycle, providing a single point of contact and access to supports for people at all ages and circumstance. The LAC role is multi-level (individual, family, agency, community) and multi-dimensional (accommodation, health, education, respite etc). LAC provides service coordination, information, advocacy, family support and direct funding to individuals and/or families - the combination of these elements means that a LAC works with a high degree of flexibility and creativity across life stages.
(1.4) Seeks to transfer decision-making power to people with a disability and their families and carers.	In the UK, The Community Care (Direct Payments) Act 1996 gives local authorities the power to make cash payments for community care direct to individuals who need services. Day-to-day control of the money and care package passes to the person who has the strongest incentive to ensure that it is spent properly on the necessary services, and who is best placed to judge how to match available resources to needs. The Cash and Counselling Demonstration, funded by the US Department of Health and Human Services, is expected to increase client autonomy, consumer satisfaction and flexibility in the type and range of supports available. The project involves offering cash options to elders and adults with disabilities, with children with disabilities also included in one State (Florida). Consumers receive a cash benefit and choose who provides personal and essential services (help with bathing, eating, dressing, etc), as well as when and how they are provided. For example, in Arkansas *Independent Choices* gives beneficiaries who are eligible for Medicaid personal assistance services (PAS) the option to receive a monthly cash allowance in lieu of traditional services. Beneficiaries may use the allowance to hire caregivers or purchase equipment that would enhance their ability to live independently. In addition to a monthly allowance, the demonstration provides counselling services (for example, to help the client develop an allowance expenditure plan) and bookkeeping services (for example, to pay and withhold taxes for caregivers hired with the allowance). Clients who are unable to manage their own PAS may have a representative (eg family member or legal guardian) do it for them. LAC in WA improves individual empowerment, through client involvement in the development and delivery of their care plan. Where individuals and families wish to self manage their funds, LAC acts as a funding conduit for a range of grants from small to larger sums for in-home/family supports that appear to demonstrate effectiveness in preventing the need for residential placement.

(1.5) *Complements and works alongside informal supports to strengthen informal support networks for families (rather than depending solely on professional support systems).*	In Victoria, key functions of Intake and Response Services (IRS) include: ⌖ Individualised responses to assist people with a disability and their carers to navigate and access community supports and services (eg by providing a contact point for people requiring information or assistance; screening of requests for access to specialist disability services; determination of eligibility; information provision about disability related issues, supports and services; referral to community supports and services; management of Service Needs Register applications; and/or short term, time limited, task focussed interventions); and ⌖ Systemic responses to create a visible, single point of contact, identify unmet need and inform service planning (eg community education; facilitating partnerships with local community supports and services (generic and specialist); maintaining accurate local information on supports and services; and assisting in identifying unmet need). LAC in WA aims to keep families and people with disabilities together and to strengthen communities. It is committed to goals of self-sufficiency, competency, control, choice and quality of life, encouraging and maintaining informal support networks and decreasing dependence on formal supports.
(1.6) Provides information and learning opportunities, including skills development	Commonwealth Carelink Centre shopfronts will be established in 54 regions around Australia, operated by a wide range of organisations, including community based, religious, charitable, private, local and state government. In addition to shopfronts, Centres can be contacted nationally through a freecall 1800 telephone network. The Centres act as a single point of contact, providing information and guidance about community care services and aged care homes available in the local community. Commonwealth Carelink Centres can provide information to older Australians, their families, carers, general practitioners, other health professionals or anyone else who needs this information. The regional focus enables each Centre to develop an awareness of the entire range of services available, to establish networks with local providers and ensure information is up to date.

2. Impacts on Need and Environmental Factors at Community, Family and Individual Levels	
(2.1) Encourages 'linked' action across all areas of government activity, improving access to generic as well as specialised services across the diversity of community living eg housing, transport, and employment.	Commonwealth Carelink Centres act as single points of contact, providing information and guidance about the full range of community care services and aged care homes available in a local community. Centres can provide information to older Australians, their families, carers, general practitioners, other health professionals or anyone else who seeks information. The regional focus enables each Centre to develop an awareness of the entire range of services available, to establish networks with local providers and ensure information is up to date. LAC in Western Australia has both individual and community focus, with part of the role of Coordinators being to expand the range of local services. Coordinators work to achieve greater understanding amongst generic services with regard to people with a disability, improve inclusion in mainstream services such as health, education and housing, increase cooperation between agencies and increase overall service delivery through decreased duplication and better targeting of resources. In South Australia, Disability Action Plans seek to achieve five 'Key Outcomes' within all government portfolios and their agencies in part as a method to increase access for people with disabilities to generic services. 'Key Outcomes' are accessibility to their services for people with disabilities; information about services/programs is inclusive of people with disabilities; advice or services to people with disabilities are delivered with awareness and understanding of issues affecting people with disabilities; provision of opportunities for consultation with people with disabilities in decision-making processes in the implementation of complaints and grievance mechanisms; and each portfolio to meet the requirements of the Disability Discrimination Act 1992 and the Equal Opportunity Act 1984.
(2.2) Takes into account the individual's environment (i.e. recognises the interplay of individual and environment characteristics) including the total family situation and needs.	Community Aged Care Packages (CACP) are a key element in ensuring that staying at home rather than entering residential care is a real option for those older Australians who choose to do so. CACPs offer an integrated package of services for frail older people and are popular as they are based on a single point of contact for people assessed as needing a range of services. In 1996 at least half the clients received assistance in the form of home help, laundry, case management, emotional support and supervision and shopping. At least one third were receiving assistance with bathing or showering, meals assistance, delivered meals and transport. LAC in Western Australia is a 'demand driven' approach to meeting the needs of people with disabilities and their families. Unlike more 'supply driven' approaches, which require a person to fit the service, supports are packaged to suit the particular requirements of the individual. Individuals and families are assessed against a three tiered eligibility framework for access to a range of supports through funded programs. For those eligible for supports a planned approach to assessing individual needs takes account of the individual's environment including the needs of the total family. LAC can then facilitate access to both generic community services and specific disability programs including family support programs where available.

(2.3) Decentralised decision-making provides flexibility and autonomy for workers including opportunities to spend time on inter-agency coordination.	The approach taken in the Commonwealths second round of Coordinated Care Trials is based on the concept of capped pooled funding in combination with individual care plans and case management. Case managers operate as a form of budget holder for services with an envelope of funds with which to purchase a mix of services. Anticipated outcomes include more efficient purchasing of appropriate services for individuals, overcoming the problems of overlapping state and commonwealth jurisdictions, increased competition between providers to perform on output efficiency and increased coordination of services. However, there are concerns regarding the impact of managed competition on the resources available to community services, reduction in the quality of care provided and cooperation between services. The Mental Health Services Crisis Management Team at Aintree in the UK was developed with the aim of reducing hospital admissions and forced removal of people experiencing an acute episode. The Crisis Team have a preventative approach, seeking to identify the client at the early stages of illness or relapse and employ behavioural cognitive techniques within a psychosocial model, using people's own skills to help them to cope. Increasing people's coping strategies reduces the need for future interventions. Teams provide 24-hr help from Registered Mental Health Nurses and Support Workers, with home visits between 9am-midnight and telephone support from midnight-9am. Referrals are accepted from any member of the multidisciplinary team that undertakes pro-active outreach to identify and work with people with high needs. Intervention strategies include the use of respite facilities, as well as added social support. A key factor in the success of the Crisis Team is the devolved authority to workers engaged in outreach, enabling them to take a range of decisions that will meet the urgent nature of symptoms and prevent the need for hospital admission.
(2.4) Incorporates a very strong principle of understanding and being guided by the individual or family's lifestyle, values and daily routines and accommodations.	Each LAC in Western Australia supports approximately 50-65 consumers, a ratio designed to ensure that consumers can be known personally and their individual needs responded to. Families have given LAC a very high rating on criteria which included being involved in decisions, choice and self sufficiency, being in control of services and supports, having a sense of security, feeling supported, satisfied and being optimistic about the future. Initiatives have evolved under LAC to better service remote communities and Indigenous populations. In evaluations, consumers liked Coordinators' good back up and support, accessibility and availability, their personal approach and willingness to get involved, and their access to funding when needed.

(2.5) Services are extensive, flexible and provide an individualised range of supports, with timing of interventions to converge and support multiple needs.	Community Support Teams in NSW are multi disciplinary teams generally comprised of professionals (such as Speech Therapists, Physiotherapists and Occupational Therapists, Social Workers, Community Nurses, Psychologists, Community Workers and Programmers) who provide a range of support services to clients, families and carers. Support services include both direct intervention and the planning and coordination of services provided to a client and his/her family or carer. Services include assessment, case planning and management, counselling, referral, therapy, family support, early intervention and behaviour management. An example previously cited, The Community Care (Direct Payments) Act 1996 in the UK, gives local authorities the power to make cash payments for community care direct to individuals who need services. Day-to-day control of the money and care package passes to the person who has the strongest incentive to ensure that it is spent properly on the necessary services, and who is best placed to judge how to match available resources to needs.

3. Increases Efficiency and Effectiveness of Service Provision	
(3.1) Increases cost effectiveness of service delivery. ***(Selected Examples)***	**Local Area Coordination in Western Australia** LAC aims to keep families and people with disabilities together and to strengthen communities. It is committed to goals of self-sufficiency, competency, control, choice and quality of life, encouraging and maintaining informal support networks and decreasing dependence on formal supports. Between 1987 and 1994 the net inflow of people from country areas to metropolitan institutions was arrested and the proportion of former country residents living in metropolitan residential accommodation fell from 18 to 12 per cent, representing a one third reduction in seven years (Cooper et al, 2001). LAC has been the subject of four external evaluations, two consumer satisfaction surveys, external audits and ongoing monitoring under the DSC Disability Services Standards. LAC was selected as an exemplary example of service reform by the Productivity Commission (SCRCSSP, 1998) and the Review of the CSDA (Yeatman, 1996): "*LAC used competition to enhance the effectiveness and efficiency of supports and services to consumers of LAC. The main competitive mechanism was the devolution of service providers to consumers. As long as the consumer has the choice of more than one potential service provider, providers should face incentives to improve the efficiency of the services that families can purchase with LAC funding*". Consumers can use funding to purchase services from a range of sources including non-government agencies or private individuals. In this way, LAC drives efficiency in the delivery of services and supports through competition and expanding the range of sources from which supports may be purchased. Service coordination accounts for approximately 10% of overall disability services expenditure in Western Australia. The return on investment may be measured partly by the capacity of LAC to facilitate access to self-help and low-intensive resources, potentially negating or delaying the need for more intensive supports (long term). LAC also leverages other generic supports,

3. Increases Efficiency and Effectiveness of Service Provision	
	thereby reducing demand for specialist disability services. According to the Productivity Commission (1998), since 1997/98 $1.48 million in accommodation support funding has been provided to 56 LAC customers deemed to be in critical need of support at an average cost of $26,464. This compares to the average cost of an accommodation facility being approximately $60,000 per place. In 1997, 60 families assessed as in critical need received $270,000 to purchase respite services at an average cost of $4,496. Less than 7% of these families required any additional funding, indicating the success of small grants in supporting carers to continue in their role and in reducing demand on other high cost options. **Commonwealth Aged Care Reforms** For aged people living at home, the major services funded by the Commonwealth, State and Territory governments include Home and Community Care (HACC) and Community Aged Care Packages (CACPs). Between 1985/86, when the aged care reform process started, and 1995/96, expenditure on HACC services increased from $233.8 million to $601.9 million in real terms, an increase of 157%. HACC services also increased their share of total recurrent aged care expenditure during this time from 15% to 22%, reflecting the shift away from funding for supported accommodation (ABS, 1999). Between 1993 and 1998, the number of people receiving a CACP increased from 211 to 8,831. In 1997-98, the annual government outlay for each CACP was $9,923 - similar to the subsidy for a low care (hostel) place at $9,360 (ABS, 1999). Also reflective of the change in emphasis from the more intensive forms of residential care, hostels increased their share of total aged care expenditure between 1985/86 and 1995/96. Their share increased from 5% to 13% over this period, while nursing home expenditure declined as a proportion of the total (from 80% down to 63%). By 1997/98, the annual cost to government (excluding capital funding) was $29,648 for a nursing home place and $9,360 for a hostel. The cost to an individual varied according to their income and assets. At 30 June 1998, there were about 57,500 people in hostels and 67,900 in nursing homes (ABS, 1999).
(3.2) Incorporates elements of training and support for professionals, staff and volunteers involved in the delivery of services.	Staff in western Australia's LAC program are provided with comprehensive orientation and training including participation in a national training program developed in partnership with Edith Cowan University. A comprehensive Supervision Charter has been developed as a bottom-up process involving people at every level from within the program. A Supervising Coordinator is provided at an average ratio of 1:8' Supervising Coordinators have a smaller allocation of consumers in order to allow them to provide other Coordinators with locally based hands-on supervision and support. The management structure is flat.

(3.3) Applies referral and assessment tools that are appropriate to the level of need and minimises (where possible) duplication in assessment and eligibility requirements.	Victoria has undertaken a comprehensive review of assessment and referral in the Supported Accommodation and Assistance Program and will be implementing improved assessment and referral mechanisms. They are moving to a regional safety net approach based on clearly identifiable 'front doors' to provide a clear pathway into the homelessness service system. ‘Front door' services will conduct an initial assessment to provide sufficient information for the agency to respond immediately to crisis, match the client with available assistance within the service and/or make effective referral(s). The features of a front door service are accessibility (highly visible and well publicised; telephone & face to face contact; a free call number; walk in capacity with appointments available but not required; staffed working hours at a minimum but with arrangements to provide an extended hours response; a welcoming non judgemental service culture, and a location close to public transport links); complementary to existing pathways (people can continue to approach any SAAP service. If unable to assist they are referred to the front door service together with a preliminary assessment); and communication and links (protocols between front door and other homelessness services; protocols with other key services in related services systems; and a clear communication and linkage strategy for state-wide and local arrangements, information and referral mechanisms). The need for specialist expertise in relation to disability types is an important area for consideration, however key findings in a review of LAC in Western Australia indicated that that there were not marked differences in experience and needs across physical, sensory and intellectual disability client groups and their families (Lewis 1991 cited in Cooper et al, 1996).
(3.4) Improves access to under-represented groups including indigenous people, people from culturally and linguistically diverse backgrounds, geographically or socially isolated families and country communities.	Four Aboriginal and Torres Strait Islander Coordinated Care Trials were conducted across five sites in three States and Territories (NT, NSW, WA). Pooled funds were used to provide individual care on a case-by-case basis and to implement community health initiatives. The principal aim of the trials was to test alternative financing arrangements and through this, improve the quality of care for those with a diverse range of health care needs. A distinguishing feature was the focus on empowerment and health system reform to achieve an improvement in the health status of indigenous communities. The model of care coordination varied across the trials, incorporating different approaches to assessment, care planning and individual case management. The trials led to greater understanding of the importance of community empowerment as a means of driving health service reform. By working with communities, LAC in Western Australia successfully increased access to supports for specific groups including isolated families and indigenous families. (However, the rate of CSDA service provision to Indigenous Australians in WA is less than the proportion of the general population (AIHW, 2001a). The Population Group Planning methodology utilised in NSW uses a number of variable coefficients to match resource allocation to service demand, including indigenous status and ‘rurality’ (population remoteness). PGP facilitates decision making through a comparative assessment of population data and geographic areas.

KEY FINDINGS

Aspects of this approach that should be emphasised in order to better meet needs and manage service demand include:

- *Strong local focus* - people who live in the geographic area in which they work can better match needs to available services and facilitate community development.
- *Multi-disciplinary assessment teams* – an assessment based on disability-factors alone may limit the capacity to identify and address the broad range of supports that families may benefit from. A multi-disciplinary approach to assessment including family context may be appropriate. Multi-disciplinary teams can be effective in assessment and referral where an objective, public, multi-disciplinary approach is taken to screening applicants for care and in service provision.
- *Consistent definitions* - key philosophical concepts underpinning program structure (such as 'strengths-based approach') should be explained in practical terms and permeate all aspects of a program. Eligibility or access guidelines should be standardised - different understandings of the concepts of impairment, disability and handicap may lead to the exclusion of some groups.
- *Pooled funds to provide packages of care* - the benefits of service coordination cannot be realised through implementation in isolation but rather through incorporation and integration within pre-existing systems. This extends to flexible funding arrangements (including providing funding directly to consumers to purchase services and supports) and the capacity to combine a range of grants in a package of measures.
- *Range of services available* - The extent to which outcomes can be achieved will vary according to the context but factors such as geographic isolation, limited investment in local decision-making capacity, limited service options, workforce shortages and limited infrastructure will tend to inhibit progress. The extent to which the service needs of individuals and families can be met effectively relies on building the capacity of organisations and the local community.
- *Workforce development* - intended results require not only continued investment in infrastructure support and information systems, but also in staff recruitment and their personal and professional development. Accumulated experience (with services, service users and the community) is a critical factor and steps should be taken to maximise retention of good workers.
- *One integrated gateway for access to all services* – a single point of contact to identify needs, inform service planning and act for people assessed as needing a range of services (with a brief at all levels within the service system and across different service types).

- *Highly individualised approach* – Coordinators need time to develop relationships and a detailed understanding of a person’s needs and circumstances. A key issue is availability and response times (to often unplanned events) – workloads need to be measured to ensure workers have sufficient time. Administrators need to be careful that efficiency drives do not compromise the program in seeking to defer the need for more intensive services.

- *Best practice approaches* - further exploration and development of evidence-based protocols for multi-disciplinary care are required to maximise the potential of this approach.
- *Breadth of the Coordinator’s role* - coordinating access to services for people with a disability should be defined to include:
  - Building relationships with individuals and families and helping them to determine their own needs, plans for the future and service requirements.
  - Assisting consumers to coordinate the provision of services (transaction administration) and monitoring the quality and quantity provided.
  - Making connections with local community members, groups and agencies and facilitating the establishment of new services and securing new funding where service gaps exist.
  - Providing information and advocacy and supporting individuals and families to develop and maintain strong informal networks.
  - Providing "grass-roots" information to those responsible for policy and funding decisions.
- *Devolved responsibility* – care coordinators should have substantial authority across the service system.

Approach 2: Family Support

1. Builds Resilience Across the Lifespan	
(1.1) Adopts a strengths-based approach to building the resources of individuals and families.	Family support programs aim to build family empowerment and coping skills, including facilitating the development of efficacy beliefs - people's individual perceptions of their ability to influence their context including self-esteem, perceived competence and motivation. In particular, they encourage help-seeking (to overcome small hurdles in providing care to a member with a disability), mastery and competency skills that includes decision-making ability and coping strategies. They also build knowledge of service systems, support options, develop communication and problem-solving skills and drive consumer-driven human services delivery models and practices that support and strengthen family functioning (Dunst et al 1993). The Strengthening Families Initiative in Victoria adopts a strengths based framework when working with families to establish goals. Service staff will reframe child welfare problems and, in conjunction with the family, identify underlying issues and resources that may be harnessed or built upon in order to contribute to resolutions. A working agreement is established with each family that, in part, seeks to cultivate family problem solving and family self-management. Service staff are afforded a high level of supervision, teamwork, staff development and staff support; Strengthening Families services have an embedded culture of reflection and place an inherent value on family feedback.
(1.2) Provides supports and resources in ways that encourage, develop and maintain healthy, stable relationships among family members with a focus on early intervention and encouraging help-seeking behaviour.	'The aims of family support programs are to enable and empower people by enhancing and promoting individual and family capabilities that support and strengthen family functioning' (Dunst et al 1993). Recent research indicates that outcomes for children with a disability are not likely to occur without clearly establishing the goal of the centrality of parent/child interactions to the early intervention process (Dunst, 2000). For example, without the encouragement and support of highly responsive interactions with their children, it is unlikely that any type of intervention that supports the whole family will have an effect on child development. Services should also ensure that the welfare and rights of children are paramount. Such a service would pro-actively foster support for parent child attachment to develop, and emphasise promoting and strengthening positive family relationships inclusive of and affirming of the child with a disability. Several family factors (including parents' stress levels, access to social supports, personal wellbeing, attitudes toward their child, opportunities to play with their child and their commitment to carrying out their child's interventions) have been identified as significant to children's development and the capacity of families to provide long term care (Dunst et al, 1989). Family support frameworks and family centred practice are now considered essential to achieving optimal outcomes for children with a disability as well as their families. The Family Support Program in Queensland aims to strengthen the capacity of individual families to meet the day-to-day challenge of caring for their child with a disability through building formal and informal supports around families, that meet the needs and priorities of family members (including by developing best practice). A facilitator works directly with the whole family to identify their needs, to assist the family to better access the formal service system and to develop informal networks within community and existing family networks. Ways that this can be achieved include providing information on formal and informal supports; providing assistance to problem solve difficulties that family may

1. Builds Resilience Across the Lifespan	
	experience; and the use of discretionary funds to help families access supports and services to manage on a day to day basis. Supports include ongoing supports (eg in home support, domestic assistance, short breaks or respite care) and one-off supports (eg purchase of equipment, household items, vehicle or home modifications). In addition, supports are available to parents and siblings including information forums, access to parent support groups, skill development workshops and counselling.
(1.3) Demonstrates a lifespan or long-term perspective, providing support either within or through transition between life stages with clear links to future outcomes.	Research that identifies best practice elements of family support programs suggests that support should be made available on an ongoing basis due to the life long nature of the disability and its impact on the child and the family. The service system should ensure provision of continuous support where needed, through stages of the life cycle. Existing family support programs serve a wide range of age-based target groups, from a 'window' of just a few years to many years, spanning a number of transition points. A number of programs, however, particularly Australian programs, limit access to services through the imposition of either narrow age restrictions, regional quotas or targeted budget savings. Other programs may seek to more effectively meet the specialised needs of particular client groups by targeting the program very precisely – but in the process create the unintended consequence that upon exit from a program, at a life stage transition point, suddenly dramatically fewer supports can be available. (Although not an example of a service that is particularly narrowly targeted) one aspect of the recent evaluation of the Queensland Family Support Program found that parents reported some planning capacity but that ideally they would like to be able to plan further ahead and clarify supports likely to be available well into the future. The Family Care Pilot Program in Wisconsin, USA, provides assistance and information to people seeking long term care (older people, people with a disability etc) including one-stop-shop access to local services and providers, counselling regarding long term care options and information on funding or income-support etc. As a precursor to this, there is a comprehensive interdisciplinary assessment of consumer needs and preferences to develop a plan of care from a lifespan perspective. Also in the USA, Lifespan Respite is a coordinated system of accessible, community-based respite care services for caregivers and individuals regardless of age, race, ethnicity, special need or situation. Respite care is planned or emergency short-term relief to caregivers from the demands of ongoing care for an individual with special needs or at risk of abuse or neglect - special needs may include any disability, any chronic or terminal physical, emotional, cognitive or mental health condition requiring ongoing care and supervision, including Alzheimer's disease and related disorders, developmental disabilities and children with special medical needs. Across Australian jurisdictions, increasing recognition has been paid to the need for programs to bridge the transition from school to adult life, particularly for those people with a disability who have not been able to access appropriate employment services immediately following completion of their schooling. Qualitative surveys of families with adolescents and adults who have a disability report substantial family stress when there is a dramatic reduction in services as a child leaves school. Transition planning typically occurs while the young person is in their final year(s) of school and is coordinated either within or in collaboration with the school and relevant teacher(s). Transition planning can include consideration of the medium and long term needs of the individual in relation to housing, employment, post-secondary education, community access, outreach & access to information, travel/transport skills and training programs.

1. Builds Resilience Across the Lifespan	
	For young people in their adolescent years, the need for 'stability planning' as distinct from permanency planning, has been proposed in the child and family welfare area. This approach involves offering a range of different kinds of living options in recognition of varying needs, but with aims of providing stability and continuity with family and friendship networks (Aldgate, Maluccio & Reeves 1989). It recognises the growth in personal autonomy and decision-making, but the need for a secure base and continuous family relationships from which the young person can experiment with increasing autonomy.
(1.4) Seeks to transfer decision-making power to people with a disability and their families and carers.	Services should give strong affirmation that to families, 'empowerment' means maximising autonomy, choice, participation in decision-making and where appropriate control and having access to services delivered with respect and a sense of partnership. Often this will entail being assisted to gain their own expertise and skills. The Commonwealth Department of Family and Community Services Stronger Families Strategy represents a commitment to strengthening families as a fundamental unit in society. This commitment is delivered through a combination of services and family-based approaches to income support, with an emphasis on government, community and family partnership. The strategy brings together income and child support payments, support services and other assistance available to families, children, young people and students. Financial assistance to families is provided in various ways, notably for families of children with disabilities through the Carer Payment (for people with constant care for a child less than 16 years with profound disabilities) and the Carer Allowances (Child) for people with significant caring responsibilities for one or more children with less severe disabilities. This approach seeks to give families control over resources by transferring decision-making and providing a range of options and can provide specialised services in a way that fits in with individual family daily routines, culture and life styles.
(1.5) Complements and works alongside informal supports to strengthen informal support networks for families (rather than depending solely on professional support systems).	Family support programs that focus on building stronger informal support networks can reduce family stress, make supports available in ways that are flexible and responsive to the entire family unit, build confidence in the 'system' and awareness of supports to encourage early help-seeking behaviour, avert crises and contribute to skills development and resiliency over the long term (Cooper et al, 2001). The Family Support Program in Queensland provides a facilitator to work with the family to better access the formal service system and to develop informal networks within community and existing family networks. The facilitator, in conjunction with the family, develops a support plan based around the individual families' needs. The program also provides access to discretionary funding for the purchase of supports or services. Currently a maximum level or benchmark of funding is allocated according to an assessed level of need but the level of discretionary funds accessed varies depending on the level of need. Families feel that the program has provided an increased flexibility in planning, increased flexibility in the use of funds and greater autonomy in decision making whereby the delivery of services is responsive to their needs (demand driven). The broad aim of Families First in NSW is to support the raising of children and help solve problems early before they become entrenched through a coordinated network of services. A part of the program features funding for local initiatives including a volunteer home visiting service and extensions to the "Schools as Communities" projects (to reduce the impact of disadvantage on children entering school by providing integrated services for families in severely disadvantaged communities), and the development of a variety of research projects and resource materials such as "Communities 4 Kids" (guidelines for strengthening connections between families and communities).

1. Builds Resilience Across the Lifespan	
(1.6) Provides information and learning opportunities, including skills development	Families need information to understand the cause, nature and implications of their child's disability in order to set reasonable expectations for the future and to begin to regain some control over their lives (Roberts 1986). Victoria's Signposts for Building Better Behaviours is a comprehensive set of materials for parents and a supporting set of manuals for workers, developed through the Intellectual Disability Parent Support Project to help families who have school-aged children with intellectual disability and difficult behaviour. The parent materials developed included eight information booklets, a video that shows examples of the strategies in the booklets, and a workbook in which parents can practice working out appropriate strategies. Parents can use the material independently, with telephone support or by attending a series of six group sessions. The worker materials are provided in three manuals. The manuals will assist the workers to provide support to families who are working through this program and will also help the workers to monitor how helpful the program is to families.

2. Impacts on Need and Environmental Factors at Community, Family and Individual Levels	
(2.1) Encourages 'linked' action across all areas of government activity, improving access to generic as well as specialised services across the diversity of community living eg housing, transport, and employment.	Family support programs can encourage 'linked' action by providing advocacy to families and assistance to access a range of other supports. If appropriately resourced, family support programs can also work at the local level to create links between services (eg schools, maternal and child health services, hospitals, family support and counselling, domestic violence services, alcohol and drug agencies, mental health services, pre-schools and kindergartens). They have the potential to enhance a sense of community: promoting the coming together of people around shared values and common needs in ways that create mutually beneficial interdependency. In South Australia, Options Co-ordination provides a single point of entry to the disability services system through five lead Options Coordination Agencies (OCA) based on disability types (Intellectual, Adults with Physical & Neurological conditions, Brain Injury, Children with Physical & Neurological conditions and Sensory). Developed in 1994/95, Options Coordination combines case management, community development and service brokerage. Options Coordination is designed to provide individualised supports to people living in the community to maintain and enhance quality of life. OCA's determine access and plan services around individuals using a standardised process that has six stages - assessment; support planning; matching support plan(s) to appropriate providers; attaching notional resources to support plans; contracting; and monitoring. Reviews have made a number of recommendations to improve outcomes and service effectiveness in Options Coordination, including having Coordinators with greater local experience, providing greater client autonomy over support packages and funding, and promoting greater coordination and consistency in processes and between OCAs. More broadly, however, programs are often not designed to allow for community based responses, though local administration and data collection could identify common needs within communities and innovative practice could encourage the pooling of funds to purchase shared resources.

2. Impacts on Need and Environmental Factors at Community, Family and Individual Levels	
(2.2) Takes into account the individual's environment (i.e. recognises the interplay of individual and environment characteristics), including the total family situation and needs.	Queensland's Family Support Program provides flexible and responsive support to families with complex needs who support a child with a disability. There is a commitment to family-centred practice in developing a support plan based on family preferences and choices. This commitment extends further than choice, seeking to build and enhance problem solving, self-reliance and self-management of the family. The program provides supports to the child with a disability as well as the whole family. A facilitator works with the whole family to identify their needs, and, in conjunction with the family, develops a support plan based around the individual families' needs. Families are then streamed into four distinct levels of need. Of particular importance to the success of such programs is the sense of partnership with families that extends to family input to planning and continuous feedback on impact of 'the system' on families. In a recent review of the Queensland Family Support Program, families reported contact with facilitators on a weekly, fortnightly or monthly basis. There was a review of the support plan approximately every 3-4 months and always within six months (Enhance Management, 2001a). Close and ongoing contact between service staff and families, planned and carried out at appropriate intervals, is imperative in encouraging a partnership approach. In addition, such contact facilitates the changing of support arrangements quickly.
(2.3) Decentralised decision-making provides flexibility and autonomy for workers including opportunities to spend time on inter agency coordination.	Victoria's Strengthening Families model comprises four components: assertive outreach, case management, in-home support, and purchasing other services (brokerage) to help families. Service staff use their professional judgement in initiating assertive outreach. They can also use brokerage funds to purchase a wide range of goods and services for families (eg utility bills, rental arrears, whitegoods, car repairs, childcare, recreation, school camps, tutoring (depending on what is deemed would be most effective in alleviating risks. Service staff also devote substantial effort to creating links between services (eg schools, maternal and child health services, hospitals, family support and counselling, domestic violence services, alcohol and drug agencies, mental health services, pre-schools and kindergartens). Lifespan Respite is a coordinated system of accessible, community-based respite care services in the USA for caregivers and individuals regardless of age, race, ethnicity, special need or situation. Nebraska's Lifespan Respite Program was implemented in 2000 by the Nebraska Department of Health and Human Services to coordinate respite care services for people with disabilities. The program is broken into six community-based programs, each serving as a single contact point for consumers who need access to respite care. During the next two years, each program will assess the specific needs of the community it serves and determine if enough providers exist to handle the need; they will then conduct marketing targeted toward families, providers and businesses to increase awareness of the program's existence and the benefits of respite care. Each program will then recruit more providers as required and develop and administer training programs for caregivers, whether they are professional service providers or families.
(2.4) Incorporates a very strong principle of understanding and being guided by the individual family's lifestyle, values and daily routines and accommodations.	Families will benefit at various times from combinations of specialist services, disability specific services and mainstream services as well as informal supports. Where change between providers is necessary and/or multiple utilisation, attention to integration and coordination will be beneficial. Where this occurs, strong emphasis should be on protecting family integrity, respecting the family's beliefs and values and protecting the family from intrusion upon its beliefs and values. For interventions to be delivered in ways that accept, value and protect the individual or family cultural values and beliefs, providers need to be culturally sensitive and networked with other agencies.

2. Impacts on Need and Environmental Factors at Community, Family and Individual Levels	
	Victoria's Making A Difference Program provides individualised funding packages that incorporate case management and financial resources to support families caring for a member with a disability in the family home. The program assists families to develop a highly individualised care plan to meet their needs and then works collaboratively with them to access a range of primary care and community services and build informal support networks in the community. Funding can be used to top up existing services, establish a new service, recruit a pool of sessional workers/volunteers, assist with holiday program or camp participation, hold information forums/ parent support groups, provide short-term loan of equipment etc.
(2.5) Services are extensive, flexible and provide an individualised range of supports, with timing of interventions to converge and support multiple needs.	Services should be guided by what the family says are their priority needs at any particular time. Services should focus on fitting in with the family life style to assist the family normalise their life as much as possible rather than the family having to change to adjust to the services. Within these parameters, the issue becomes access to appropriate services and efficiency of administrative arrangements to facilitate that access. The range of supports that could be managed through family support programs include respite care, early childhood intervention, home-based support, parent education and empowerment, support groups, counselling/ therapeutic & cognitive interventions, and behaviour intervention. In some locales, some types of services will not be available and alternative arrangements need to be considered. Sometimes a 'shopping trolley' approach will be required in order to effectively meet a families (changing) needs – as different services are required, a family needs to be able to obtain 'bits of this and bits of that' and the administrative process to support that needs to be simple and quick. A further aspect is the diversity of uses for which funds (in programs that support such approaches) can be applied. For example in a recent evaluation of Queensland's Family Support Program, recipients nominated a broad range of expenditures as being effective in meeting their needs, including respite care, household items, household improvements and/or modifications, specialized equipment, therapy counseling services, domestic services, clothes, transport, medical costs and education seminars. Focus on building informal supports and making small purchases relies on the provider's skills in giving advice and having knowledge of the range of purposes for which the funds may be used. Within the definition of 'family support', it is appropriate to emphasise two particular forms of service that can have significant impact upon a families capacity to continue to care for a family member with a disability at home: ⌖ Challenging Behaviour - models and technologies for assisting parents with prevention of challenging behaviours have been developed. Recognising the powerful role of parents in preventing problem behaviours, incidental teaching and positive programming are specific strategies for parents, which can be effective in preventing problem behaviours (Victorian Parenting Centre1999). Positive approaches to behaviour management, including pro-active behaviour change strategies (eg environmental and antecedent manipulation, skills building and reinforcement-based approaches) have proven highly effective in modifying challenging behaviour including aggression. Families may need training in safe and effective strategies for responding to aggression when it occurs while longer-term preventative strategies are put into place (Adams & Allen, 2001). Such training has been shown to have a variety of positive effects, including the reduced need for physical intervention and emergency medication, reduced carer and individual injuries, and reduced breakdown of caregiver relationships.

2. Impacts on Need and Environmental Factors at Community, Family and Individual Levels	
	⌖ Short-term Care - contemporary short-term care programs are moving away from traditional overnight respite provided in residential or centre-based facilities. Models of respite care increasingly provide a mix of options, including host carer/family respite (paid carer schemes are emerging as a solution to the problems of finding families appropriate and willing to take children with disabilities and the often high daily support needs (Baldwin & Carlisle 1994); in-home care; day and evening outings with an attendant to access community facilities and groups; holiday programs, camps, short stays with other families, and taking children with disabilities on holidays; cooperative sitting services among families of children with disabilities; and staff accompanying families on holidays.

3. Improves Effectiveness and Efficiency of Provision	
(3.1) Increases cost effectiveness of service delivery. ***(Selected Examples)***	Much, though not all, of the literature reported in this project uses the child remaining in the family home as the main criterion of success. Very little work has been done on outcome measures which take account of impact on the whole family, and over the longer term rather than short-term (Cooper et al, 2001). The effectiveness of programs has been inferred from data such as take-up rates, with the impact of many specific programs the subject of current or planned evaluation. Some programs demonstrate ongoing monitoring of the quality, effectiveness and changing needs of clients over time, which allows for ongoing evaluation of the mix of supports and services provided and the identification of local needs or opportunities for community initiatives. One of the goals of the approach is to prevent increased need or dependence and build resilience over the long term. By connecting families to the service system and facilitating access to other programs there may be an increase in demand for home-based or family supports such as respite or early intervention. The efficacy of this model in preventing or delaying the need for more intensive supports, particularly residential care, and in decreasing unmet need for services over the long-term is yet to be demonstrated. However, a long-term reduction in demand for out-of-home placement and other more intensive service models as a result of increased resilience might be predicted. Research has demonstrated that providing an extensive, flexible and individualised range of formal family supports can reduce the need for out-of-home placement of children with disabilities (Gordon 1999). Other significant benefits of family support programs, when compared to providing stand-alone services (eg respite, equipment, transport) include: ⌖ The capacity to meet a diverse range of needs that are otherwise difficult to anticipate and address. ⌖ The flexibility to apply resources to physical or social needs. ⌖ The capacity to mobilise resources and support building systems that enhance the flow of resources in ways that assist families with parenting responsibilities. ⌖ Comprehensive coverage of the range of needs likely to impact on family resilience recognising the considerable heterogeneity among families with children with a disability.

3. Improves Effectiveness and Efficiency of Provision	
	Cost effectiveness of family support programs can be considered in a variety of ways: ⌖ Prevents out of home placement for children (and potentially adults if extended across the lifecycle). ⌖ Facilitates access to self-help and low-intensive resources, potentially negating or delaying the need for more intensive supports (long term). ⌖ Leverages other supports, reducing demand for specialist disability services. ⌖ Drives efficiency in the delivery of services and supports through competition and expanding the range of sources from which supports may be purchased. An evaluation of the Victorian Making a Difference program by McVicar & Reynolds (1996) found that some families indicated that if the program had not been provided their child would have been at risk or they would have no longer been able to continue caring for their child. These families also considered that continued support from the program was essential to prevent family breakdown and to enable them to continue to care for their child. Service coordinators considered that one quarter of the 35 families surveyed had a high likelihood either of not being able to continue to provide care at home and/or of the child being at risk. One third of the families were considered to be seriously at risk of not being able to continue to provide primary care if the service were to be withdrawn. Short-term assistance packages are targeted at an average of $1,175 per family for three months (range $200-$3,000). Intensive supports are targeted at an average of $4,700 per family (range ($1,000-$10,000). Once regional allocations are made, targets allow each region to determine the number of people with a disability who will be able to be assisted by the program each year. The average cost of providing intensive supports has proven to be substantially lower (typically less than half) than residential care. The Queensland Family Support Program provides a range of supports from one off supports up to a maximum of $5,000 for non-recurrent families to ongoing supports ranging from $10,000 to $30,000 per annum, which includes the facilitator and discretionary funds component. Current out of home placements for children with disabilities in care cost $70,000 and above (Disability Services Queensland, 2002). In-home support provides the carer with respite from direct care, including care during the night. Additional support such as intensive personal care can also be provided. It is seen that by providing additional support to the carer, there is a decreased possibility that the carer will be unable to cope and thus seek to relinquish care of the child with a disability. Once school age is reached, this support can continue and after hours school care where carers have full time employment can also be provided. Additional transport assistance is also available. The additional support also enables many carers to keep working in full or part time employment and therefore maintain the family unit and support the child with a disability in their own home.

(3.2) Incorporates elements of training and support for professionals, staff and volunteers involved in the delivery of services.	The relative success of family support programs depends on the availability of services and supports in the local community and the skills of the provider in suggesting solutions to family needs (including awareness of equipment or aids, knowledge of services available, and understanding the family experiences). Services should affirm the role for professional expertise, and the importance of staff having an understanding of the disability condition and its impact on the child's functioning. They should also have knowledge and skills in working with families, to be able to tailor assistance that takes account of the mix of formal and informal assistance that responds adequately to the family and the child's needs. In the recent evaluation of Queensland's Family Support Program the performance of the facilitator was rated as the most important factor in the success of the program (having characteristics such as being caring, trusting, supportive and considering the child/children and the whole family). In NSW, The Early Childhood Intervention Coordination Program involves the NSW Departments of Ageing, Disability and Home Care, Community Services, Education and Training, and Health in association with non-government organisations. Governed by a statewide Committee, Area Committees and Local Committees, the Program facilitates communication between families, service providers and policy makers to enable coordination of early childhood intervention services. The approach seeks to achieve early identification of children and families who need support, provide information to families about available services, ensure that quality services are provided and provide a mechanism for planning services to meet the needs of the child and family. The Program has developed a Manual and Training Package entitled 'Recommended Practices in Family Centred Early Childhood Intervention', established an Infoline to access a database of over 500 early intervention services, provided education programs to families and service providers and facilitated shared resources between services.
(3.3) Applies referral and assessment tools that are appropriate to the level of need and minimises (where possible) duplication in assessment and eligibility requirements.	Service systems claim to be family focused, however eligibility is often defined on the basis of the child's needs. According to Kelly et al (1995) such services may not be sensitive to those families that have complex needs and where the aim of reducing overall stress (whether it is related to the care of the child or not), would facilitate their continued care for their child. The evaluation of Victoria's Making a Difference Program recommended that working with families with the highest need of support should include families where the actual care of the child may combine with 'constraints, limitations or pressures on the family's caring capacity' resulting in high levels of stress and 'significant vulnerability in ongoing capacity to provide effective care at home' (McVicar and Reynolds, 1996). Gordon (1993), reviewing research as a basis for family support program development, concluded that eligibility criteria must take into account the family situation as well as child issues. Access to more flexible types of family support is usually based on relatively simple eligibility criteria; access to the more intensive forms of family support is typically based on a needs assessment that is comprehensive and may be undertaken by an interdisciplinary team and/or may be based on a well-developed tool. In Queensland's Family Support Program, families respond to advertised funding rounds and some families self-refer in between rounds. Applications are considered locally and regionally by priority panels. In Wisconsin USA, the Family Care Pilot Program seeks to simplify and streamline access to intensive family supports and long-term care. The pre-existing service system was diverse with more than 40 state and locally funded programs with varying eligibility requirements providing a flexible range of services. The Pilot has the potential to transform care management by increasing integration in acute and primary care needs as well as social needs

	through the establishment of two agencies in each local area: *Care Management Organisations* (CMOs) and *Resource Centres* (RCs). The CMOs undertake a comprehensive interdisciplinary assessment of consumer needs and preferences to develop a plan of care. CMO's use a network of local providers to put together care plans, they monitor the quality, effectiveness and changing needs of clients over time.
(3.4) Improves access to under-represented groups including indigenous people, people from culturally and linguistically diverse backgrounds, geographically or socially isolated families and country communities.	The degree to which a service provides culturally appropriate support is likely to rely on the cultural sensitivity of the provider and their capacity to network with culturally specific agencies. The Alternative/ Host Family Model in NT seeks to prevent the entry of children with disabilities into State care. Historically children with a disability requiring alternative care have been placed in either residential settings managed by non-government organisations or live with foster parents where the placement is managed by the Family and Children's Services Program. Parents with children with disabilities that surrender care of their children often do so without the benefits that could be provided under the substitute care system. The aim of the Alternative/ Host Family Model is to ensure that the family remains in control of the decision making in respect of the child and linkages between parents and child are kept intact. Families are involved in the selection and identification of the alternative/host carer (if possible). Carers would be assessed (by non-government agency) for care of the particular child and the family would provide respite to the carer. (Note that identifying people who are willing to provide alternate care has been difficult).

KEY FINDINGS

An early intervention approach to Family Support involving packages of support designed to meet holistic family needs may enhance achievement of outcomes for families and the person with a disability. Aspects of such an approach that should be emphasised in order to better meet needs and manage service demand include:

- *Close and ongoing contact* – a coordinator should work directly with the whole family with contact planned and carried out at appropriate intervals, particularly if support needs are prone to fluctuation.
- *Continuous support* - family support programs have a capacity to be provided across the lifecycle and can build capacity and family and individual resilience over the long term. Services (and consequently care planning) should aim to be ongoing, including facilitating and developing long-term planning throughout the child's development through to and into adulthood.
- *Early intervention* - services should be available to parents at the first indication that there is likely to be a disability. To circumvent delays in admission to services (eg difficulty with regard to diagnosis; length of wait for assessments), eligibility should rely on para-professional advice (eg early childhood professional or maternal health nurses) as evidence of disability until medical and formal assessments can be undertaken.
- *Family self-management* - participation in decision-making and where appropriate control of services delivered is important in assisting families to gain their own expertise and skills. A goal of services should be the development of a family support framework (viewed as essential to achieving optimal outcomes for children with a disability as well as their families) that seeks to cultivate family problem solving, enhance and promote individual and family capabilities, and strengthen positive family relationships. Such a framework would feature family feedback as a central construct.
- *Relevant information* - families need locally relevant information and support to access information where required, to assist them to understand the service system and acquire the services they need. This includes information about the nature and implications of their child's disability so that they may set reasonable expectations for the future.
- *Transition support* – it can sometimes be the transition between life stages for the person with a disability rather than the stages themselves where family resilience is most tested. By extension, major events or transitions for the family unit as a whole should also be considered as important times to focus service responses (consider medium to long term needs in relation to housing, employment, travel etc).
- *Staff support* – optimum staff performance and the maintenance of consistency across the service requires high levels of supervision, teamwork, staff development and staff support.

- *Challenging behaviour* - models and technologies for assisting families with management and prevention of challenging behaviours should be featured, including training in effective strategies where possible.

- *Flexible short term care* – respite should be provided as part of a coordinated, integrated package of support for families, rather than as a single type of support provided only on an emergency basis. In addition:

    - Services should be able to provide both regular planned respite and be responsive at short notice when unpredictable needs arise.

    - Services should be able to be supplied in a variety of ways (e.g. facility based, host carer/family respite, paid carer schemes, in-home care, day and evening outings, holiday programs, camps and short stays with other families, cooperative sitting services among families of children with disabilities, and service staff accompanying families on holidays.

- *Care Plans* – assessments should have a dual focus on individual needs and the needs of the carer or the whole family as a unit. This is consistent with research findings that supporting carers is critical to providing stable environments and maintaining informal supports. The care plan should be based on family preferences and choices. A network of local providers should be consulted and involved in development of the care plan.

- *Complex needs* - family support programs have the ability to address complex care needs (including severe or multiple disability, challenging behaviour and where multiple, flexible service responses might be required). They can also recognise and respond to risk factors with regard to family coping or well-being and address urgent support needs or needs subject to rapid change which may be difficult to accommodate in other services.

- However, some issues that need to be considered in implementing or redeveloping family support services include:
    - The capacity of the approach to provide choice and to meet family needs depends on the availability of supports and services in the local community and the skills of the coordinator in suggesting solutions to family needs.
    - Should the service be auspiced through a statewide coordination program, an approved specialist disability service, or as a targeted component of generic family support services?
    - Pooling of funds and investment in infrastructure appears more applicable to larger regions than smaller communities.
    - Issues with governance and potential conflict of interest may arise if the same agency assesses care needs and provides services or receives funding on behalf of an individual.
    - Flexible and packaged services present a challenge for quality systems.
    - The age limit applied in family support programs is typically 18 years, yet families report considerable stress through the transition from school to work or post-school options. There may be value in providing extended transition support (eg two years) or raising the age limit to 25 years.

Approach 3: Independent Living

1. Builds Resilience across the Lifespan	
(1.1) Adopts a strengths-based approach to building the resources of individuals and families.	In the Supported Accommodation Assistance Program in South Australia, Independent Living Support Teams assist and support young people who will need support to access housing, develop skills in household management and adjust to independent living. The target group is 15 to 18 year olds who are under the guardianship of the minister, young offenders, or assessed as 'at-risk adolescents' by Family and Community Services. The service is characterised by a very 'hands on' approach, focused on supporting young people (as opposed to 'doing it for them'). It is concerned with an experiential/practical/ alongside approach to learning. Workers receive training in very practical skills to enable this (eg housing maintenance, choosing electrical goods, moving furniture). It provides a very discrete type of support in independent living (other types of support continue to be provided by social workers). Features of the approach include a strengths based assessment regarding their readiness to live independently, and their willingness to be involved. Another important element is skills training, in areas such as budgeting, cooking and hygiene - these activities are individually tailored to each young person and are highly flexible.
(1.2) Provides supports and resources in ways that encourage, develop and maintain healthy, stable relationships among family members with focus on early intervention and encouraging help-seeking behaviour.	The Home and Community Care (HACC) program is a central element of the Federal government's aged care policy, providing community care services to frail aged and younger people with disabilities and their carers. HACC funds a wide range of State and Local Government agencies and non-profit organisations. The aim of the HACC program is to enhance the independence of people and avoid their premature or inappropriate admission to long-term residential care. The type of services funded through HACC include community nursing, paramedical services, meals on wheels and day centre-based meals, home help, personal care, home modification and maintenance, transport, respite care, education and/or training for service providers and consumers, assessment and/or referral services, information and advocacy services, and social and carer support. Providers have flexibility in their approach to assessment and access provisions, allowing some local adaptation. HACC is an example of an early intervention service; it has been suggested that the effectiveness of HACC can be enhanced when initial requests for support can be met quickly by service providers. This can serve to encourage help-seeking and problem solving, increasing the likelihood that low levels of support will enhance individual and family coping, preventing crises that may lead to the need for more intensive supports to be provided.
(1.3) Demonstrates a lifespan or long-term perspective, providing support either within or through transition between life stages with clear links to future outcomes.	Supported living is typically provided on a long-term basis with the flexibility to review the amount and use of funds provided as needs change. In most supported living programs, once funding has been allocated to an individual it is provided on a long-term basis until the individual requires alternative care arrangements such as aged care or residential care. The principles underlying this approach are illustrated by the objectives of the HomeFirst Program in Victoria. The objective of HomeFirst is to provide home and community-based support services, essential goods and equipment to enable individuals with a

1. Builds Resilience across the Lifespan	
	disability to live independently and not require staffed residential accommodation; remain living in their own homes; increase or maintain maximum independence; move to more integrated living arrangements (eg leave the family home, rehabilitation centres or residential facilities); or access community activities and facilities. The degree to which support is provided with a focus on building the skills of the individual to maximise independence and resilience over the long-term may be dependent on the skills and commitment of the individuals providing support. Agencies that have a strong commitment to individual empowerment and long-term skills development are more likely to achieve positive outcomes. This review found little evidence of services specialising in the transition phase. Many programs appeared have a narrow focus on specific types of support, making them unlikely to have the capacity to coordinate the skills development and learning opportunities that might make substantial differences to an individual quality of life over the long term. Indeed, there may be a role for service models that focus on the transition phase and have as their goal the achievement of individual outcomes in relation to independence and living skills development. When people first leave the family or service to live independently there is the potential to build individual resilience to circumstances that might otherwise trigger the need for more intensive services in future. This is particularly relevant to young people and adolescents but may also be worth testing for effectiveness with older client groups. In the US, transition to independent living is incorporated in transition planning for school leavers as a natural planned progression for young adults. The ongoing case management or advisory function of the service provider is an important component of this approach (and may extend to increased focus on retirement planning).
(1.4) Seeks to transfer decision-making power to people with a disability and their families and carers.	The goals of individual funding approaches typically include increasing service user autonomy, control and satisfaction, as well as increasing flexibility in the type/range of supports available to people with a disability. There is strong evidence of increased consumer satisfaction with consumer-directed approaches to the delivery of home-based care and long-term care. In an international review of approaches to consumer-directed long-term care, Tilly et al (2000) found evidence of increased consumer satisfaction with control over supports and resources. This was particularly the case in programs that paid a cash benefit. A Dutch study also found that beneficiaries directing their services had significantly more influence over services, choice of provider, method and timing of service delivery, and freedom of choice than matched controls receiving care from agencies (Woldringh and Ramakers 1998 cited in Tilly et al, 2000). Research in the US that compared client-directed approaches and professionally managed approaches to the delivery of home based care to older people and people with a disability (Doty et al, 1999) found that, whereas both the consumer-directed and professional management models of delivering supportive services to the aged and disabled produce positive client outcomes overall, the consumer-directed model outperforms the professional management model on several key measures of client satisfaction, empowerment, and quality of life. There is also early evidence of high levels of consumer satisfaction reported in early evaluation of the Cash and Counselling Trial in Arkansas and increasing take-up rates of Direct Funding in the UK.

1. Builds Resilience across the Lifespan	
	Elsewhere, service coordination agencies (Specialist Counselling agencies in the US; Local Authorities in the UK and Service Coordination agencies in Australian programs) have the role of assessing individual needs, allocating funds and developing support plans or packages with the individual. There is a strong commitment to pass control regarding the use of funds and the supports purchased from the agency to the individual. In some cases, the funds are paid directly to the individual with no conditions; in others the funds are paid directly but only when there is an agreed plan for their use which may include restrictions on where services can be purchased (eg excluding the payment of relatives - UK); and in still other cases the service purchases the supports on behalf of the individual or provides the funding to a service provider to do this, on the basis of an agreed support plan developed with the individual (HomeFirst, Victoria). The greatest flexibility is evident in the Cash and Counselling Trial in the US - this program has very few restrictions on the use of funds and includes allowing individuals to pay informal carers including relatives. Australian programs tend to more restrictive, limiting the use of funds to the purchase of supports to approved service providers and/or individuals hired directly by the individual. Individual funding approaches provided through a broader service coordination approach (eg Local Area Coordination) can offer a continuum of options from direct payment to the individual through to full management of the package of supports by the planning agency.
(1.5) Complements and works alongside informal supports to strengthen informal support networks for families (rather than depending solely on professional support systems).	An independent living approach can be planned and supported in a way that retains or harnesses informal supports provided by family members or social networks, rather than an 'all or nothing' transition to formal services. One of the challenges is managing family expectations with regard to the amount of assistance available and the responsibility for care transferring to the service provider. Another is ensuring that families are not overwhelmed with the management and provision of supports, or pressured to continue to provide high levels of support due to funding limits. A high ongoing reliance on informal carers may jeopardise the long-term sustainability of the arrangements. This could lead to crisis and the need for intensive supports or residential placement that could otherwise have been avoided if a sustainable balance was struck. Support assessments typically include a review of the informal supports available to the individual and seek to maintain and enhance these supports where possible. Funds are directed to gaps or unmet needs rather than the replacement of informal supports. Where possible individuals may be maintained within the family context or assisted through the transition to independent living with ongoing involvement and assistance from relatives and friends. Coordinated supports and care plans can include a mix of informal and formal supports that may regularly change over time. By allowing for the engagement of informal carers and individually hired carers as well as services, this approach has the potential to provide more stable care arrangements, through better collaboration between informal and formal supports, more personal relationships between individual carers employed by the person or the family and lower turnover in carers (Tilly, et al, 2000; O'Brien 1993, Kulgin et al 1996). However, it should be noted that Australian and UK programs often preclude the payment of informal carers (eg family/friends) unlike European and USA examples of consumer-directed home care models in which over half the individual funding provided is typically used to pay informal carers who are usually family members (Tilly et al, 2000). In Germany, most stakeholders view the cash payment primarily as a mechanism to support informal caregivers rather than a means to purchase services.

1. Builds Resilience across the Lifespan	
(1.6) Provides information and learning opportunities, including skills development.	There is a growing recognition that computer technology and the Internet have a tremendous potential to broaden the lives and increase the independence of people with disabilities, including expanding employment and education opportunities. The capacity of the Internet to also provide access to information and peer support for both people with a disability and their families has been identified (see for example: Brodie, 1995). The provision of adaptive aids for computers is already a mainstay of assistive technology programs, however, significant additional potential is believed to exist.

2. Impacts on Need and Environmental Factors at Community, Family and Individual Levels	
(2.1) Encourages 'linked' action across all areas of government activity, improving access to generic as well as specialised services across the diversity of community living eg housing, transport, and employment.	Independent living approaches need not seek to provide all of the supports an individual may need but may work to facilitate access to generic as well as specific programs (eg Independent Living Centres, HACC). For example, clients of the *HomeFirst* program in Victoria may also be provided with case management services through Disability Client Services and may access a range of generic as well as specialised services. It is critical that the support planner or adviser has extensive knowledge of the local service system in order to refer individuals to other programs. There is also the potential for support planners to play an important role in identifying gaps, unmet needs and local community development opportunities to improve service links. This is enhanced when the support planning function is locally based but well supported by information systems and opportunities to network with other support planners to share ideas and examples of problem-solving. Opportunities to strengthen this approach include cross-program initiatives with other sectors such as Housing, Transport, Child Care and Aged Care. Supported living approaches also have the capacity to provide effective planning through major life transitions such as leaving the family home or retirement and to link supports available through other government programs if there is appropriate commitment at higher management level to ensure program guidelines and policies do not limit collaboration.
(2.2) Takes into account the individual's environment (i.e. recognises the interplay of individual and environment characteristics), including the total family situation and needs.	Stability or safety-net support is particularly important for families when any change in the daily routine of a family member with a disability may impact on the workforce participation of other family members. Family preferences for services that offer stability with regard to maintaining daily routines are recognised as a legitimate need (but do not result in restricting the options for people with a disability who have high support needs). One approach to addressing this issue is coordinated packages of employment support and day programs, possibly incorporating other supports such as transport or personal care. This was the basis of the REAL Options model proposed in 1995 by a sub-group of the NSW Council of Intellectual Disability - a framework based on zero exclusion and individually tailored supports, incorporating funding from different government sources pooled to purchase a package of supports that might include training, employment, day programs etc.

2. Impacts on Need and Environmental Factors at Community, Family and Individual Levels	
	A similar example operates in the US state of Massachusetts that involves coordinated funding arrangements through an agreement across departments. The key feature in this approach is a multidisciplinary assessment that takes into account the circumstances and needs of the person with a disability, the family and carers.
(2.3) Decentralised decision-making provides flexibility and autonomy for workers including opportunities to spend time on inter agency coordination.	There is substantial variation across programs with regard to the autonomy of local decision-makers, but (however styled) Individual Options Coordinators, Local Area Coordinators and Counsellors all undertake assessment, allocate funds and work with the individual to develop personal support plans and set in place the necessary arrangements. Decisions regarding the amount of funding to be made available to an individual is generally delegated to the local coordinator within policy guidelines (and decisions regarding the use of funds by the individual or on their behalf is made collaboratively with the individual and possibly their family or support network). In these examples, the coordinator may act as an adviser or as a broker, negotiating and purchasing supports where required, although some programs restrict the degree of autonomy in decision-making through program guidelines. Opportunities may also be limited by local area characteristics (eg the availability of support workers for direct hire) and the local services that are available. In cases where services are highly standardised or in high demand, flexibility may also be diminished. The capacity of the coordinating agency or broker to create new service agencies or influence the local service delivery profile by using pooled funds or establishment grants can be significant to the effectiveness of this approach.
(2.4) Incorporates a very strong principle of understanding and being guided by the individual family's lifestyle, values and daily routines and accommodations.	O'Brien describes supported living as "expresses a fundamentally different relationship to people with disabilities than most other approaches to services do: instead of controlling people to fix (train habilitate, rehabilitate, treat) them, supported living workers seek to cooperate with people with disabilities in order to develop the assistance they need to get on with their lives." Features of this approach include flexibility and responsiveness to individual need, maximising individual choice of support and service providers, and consistent and ongoing relationships between the Service Coordination staff and the individual. A range of tools are available to assist coordination agencies to employ a person-centred planning approach to develop support plans collaboratively with the individual and their family members or significant others.
(2.5) Services are extensive, flexible and provide an individualised range of supports, with timing of interventions to converge and support multiple needs.	Supported living approaches can either allocate funds for a fixed menu of services or they can allocate funds that may be used in a diverse and flexible way to purchase supports. The latter approach appears to be increasingly favoured in the literature, but the former approach is more common in practice. Independent living supports purchased by individuals may include paid caregivers (eg personal care), home help (eg cleaning or maintenance), skills development or assistance with household management, equipment or technology that may enhance their ability to live independently, transportation, community access and social supports, health or medical services, recreation or leisure services. In some cases it may be used to hire caregivers directly and/or to reimburse informal or family carers.

3. Increases Efficiency and Effectiveness of Service Provision	
(3.1) Increases cost effectiveness of service delivery. ***(Selected Examples)***	Our analysis suggests that supported living programs are generally allocating much lower levels of funding per person than full-time residential care models or crisis response services, but the costs are comparable in the short-term to alternative means of providing community-based care through non-government providers. In some programs (eg HomeFirst, Victoria) there is the capacity to pool resources across individuals, with their agreement, to better meet support needs and maximise the use of resources. For example individuals may choose to live together or share support workers. Commonly cited areas of cost savings in this approach include: ⌖ Maintaining informal supports which reduces the amount of formal services needed. ⌖ Reduced costs associated with the direct employment of support workers, avoiding agency overhead and administrative costs. ⌖ Identifying innovative support options and providing flexibility (eg reducing support needs through the use of assistive technology, cross program referral and pooled funding initiatives). ⌖ Portable funding promotes competition between service providers with regard to price and quality (although this is refuted by some researchers who argue that people rarely leave a service provider once arrangements are in place and that they are reluctant to dismiss unsatisfactory support workers if there is a labour shortage). Average cost per placement for the year 1999-2000 was established by the Steering Committee for Review of Commonwealth State Service Provision. Institutional accommodation delivered through government providers cost $72,778 average per place and through non-government providers the average was $29,973 per place. For community accommodation and care delivered through government providers the average cost was $74,711; when delivered through non-government providers it was $39,683 per place. The Queensland Adult Lifestyle Support Program has three bands of funding: High $50,000-$90,000, Medium $20,000-$50,000, and Low of up to $20,000. Both the Victorian HomeFirst and the Tasmanian Individual Options programs provide funding for up to 34 hours per week of support. South Australian Options Coordination provides support packages from $3,000 to $80,000 with an additional 10% for country clients. The ACT funds Individual Support Packages up to the value of $50,000 per annum (figures drawn from responses by jurisdictions to the AIHW survey on the use of unmet needs funding, 2002). The Centre for Developmental Disability Studies (Ageing and Disability Department NSW, 1999a) compared quality of life indicators and financial costs between the most common living options for independent adults with a mild to moderate intellectual disability - group homes and semi-independent accommodation. A range of lifestyle and satisfaction outcomes were compared - participants living semi-independently enjoyed significantly better outcomes on several factors and there were no outcomes on which group home residents fared better. Despite the closely matched skills and needs of residents, those in group homes received considerably higher support without demonstrated better outcomes. As an annual cost, the cost per person in the group

3. Increases Efficiency and Effectiveness of Service Provision	
	home was $64,105 compared to $16,042 for those in semi-independent accommodation. In the service models reviewed as part of this project, in only one case (Cash and Counselling, USA) was cost reduction a driving factor (and even then it was relatively minor - reduced administrative expenses as a result of cashing out benefits). However, the cost benefit of maintaining people in the community rather than residential services is recognised and costs are contained to the equivalent of existing services. In all cases, the move to individualised funding has taken funds previously directed through particular programs (eg home based care, community based options) for specific supports and made them available to individuals based on the same eligibility criteria to purchase similar supports in a more flexible way. Evidence to-date suggests that in the short-term moving to individual funding arrangements is likely to be cost neutral at best but over the longer term savings can be made (Foster, 2000). Payment rates for consumer-directed care are much lower than for agency-directed care, partly due to the lack of agencies' administrative overhead and partly because workers receive less in the way of health benefits, vacation, and other fringe benefits, in the examples reviewed, workers' hourly wage rates did not appear to differ between models (Tilly et al, 2000). A study by the Centre for Developmental Disability Studies (reported in Ageing and Disability Department NSW, 1999a) examined the equipment needs and costs for 200 adults with cerebral palsy. Equipment aid was revealed to be very important for people with a mild disability in terms of independence and social participation. The upfront outlay of funds presented a cost saving in the long-term if no or low levels of attendant care were needed.
(3.2) Incorporates elements of training and support for professionals, staff and volunteers involved in the delivery of services.	It is important that service workers are well networked and supported. Within the service models reviewed, the training and professionalism of service delivery staff is either the responsibility of service provider agencies or the individuals hiring workers directly. One of the concerns with the latter approach is that it destabilises the employment of support workers and may have a negative impact on working conditions if individual clients hire workers directly for relatively short hours etc. Alternative strategies are to use only approved service providers for purchasing supports, but this limits the flexibility and potential efficiency benefits of the approach. Another strategy is to have a 'register' or 'bank' of support workers with appropriate qualifications, experience etc that may be employed centrally but hired to individuals on an hourly basis (eg the Netherlands Alpha-Helper Model).
(3.3) Applies referral and assessment tools that are appropriate to the level of need and minimises (where possible) duplication in assessment and eligibility requirements.	Individual funds are generally allocated on the basis of a comprehensive individual assessment within bands or levels of funding prescribed by the program. These bands or levels of funding are often comparable or contained to the funding available under existing models they replace. In some cases funds have been pooled from a range of programs to be provided as a 'package' of funds available to an individual. A more detailed assessment of individual needs is typically required to determine the appropriate level of funding to be provided to the individual. The *HomeFirst* program in Victoria emphasises the importance of maintaining case management in the broader service system to ensure that living supports are seen as only one component of support provision in the broader context.

3. Increases Efficiency and Effectiveness of Service Provision	
	The regular reassessment of support provided to individuals has been identified as a significant mechanism for increasing the overall capacity in long-term care programs. It is not uncommon for allocated supports to continue at the same level over the long-term with little reassessment unless the client or carer requests additional or alternative arrangements. Turvey & Fine (1996) report that research and changes introduced to home care services in a number of European countries has demonstrated the potential of using an ongoing reassessment strategy. For example, in Britain, computer modelling of service provision data was used to predict the impact of three different targeting strategies on the use and outcome of home care. Regular assessments of all clients and the discontinuation of services to a relatively small proportion of those who were found to no longer require assistance (assumed to be approximately 10% every six months), proved to be a more effective means of extending service coverage than other approaches to the targeting of services which served to exclude important client groups from receipt of any service. After five years, the costs of service to the population without reassessments was found to be approximately 1.5 times that of assisting the population remaining after regular reassessment.
(3.4) Improves access to under-represented groups including indigenous people, people from culturally and linguistically diverse backgrounds, geographically or socially isolated families and country communities.	Encouraging consideration of pooling funds to develop shared resources or new service models may be particularly important in country areas and for servicing particular groups such as indigenous communities or people with a shared cultural background. The skills of the Service Coordinator are likely to be important to the capacity of the approach to respond to under-represented groups. Also, the availability of services and supports are likely to impact on outcomes in country areas. It may have some benefits by allowing individuals the flexibility to hire support workers with a common cultural background or from the local area (country areas). However, it may be quite unsuited to remote communities, it may not overcome social isolation as well as other service models and it may prohibit or make difficult local community development approaches. In 1995, Baume & Kay suggested that for some people participation in the open labour market might not be achievable. Since then, various research and program initiatives have been documented that may refute this claim. In a comprehensive review of the economic circumstances of people with a disability in Canada, Fawcett (1996) challenges the notion of "unemployability" of persons with disabilities - employability has as much to do with environment as it does with disabilities. Moreover, both environments and disabilities change over time. Fawcett (1996) estimated that about 56% of persons with disabilities not in the labour force showed some sign of work potential and that fewer than five per cent of people who were out of the paid labour force showed absolutely no sign of potential involvement. In the USA, some open employment services adopted a zero exclusion policy and successfully placed people with severe and profound disabilities in open employment. Tuckerman (2001) describes a demonstration project at Job Support in NSW that provided employment support to 30 Post School Options (PSO) participants with a moderate to severe intellectual disability. Of these, five returned to PSO, five did not achieve employment within the life of the project, and 20 were placed into employment with 18 remaining employed two to four years later. Although a relatively small sample, this study suggests that employment is a reasonable goal for many PSO clients.

KEY FINDINGS

Aspects of this approach that could be emphasised in order to better meet needs and manage service demand include:

- *Consumer direction* – providing increased autonomy and power in the hands of beneficiaries and informal caregivers through mechanisms such as cash payments or vouchers to purchase services. Related issues include:
  - Whether consumer direction should be restricted to a minority of clients (primarily younger adults) deemed to be capable of hiring, firing and giving direction to their workers. Doty et al (2000) found no evidence in support of restricting availability of the consumer-directed model.
  - That such programs would be so desirable that demand and expenditures will increase uncontrollably. A review of programs across five countries found that in none was expenditure out-of-control, through the use of strict limits on eligibility, benefits and funding (Tilly et al, 2000). A key aspect would be the development of measures of ability to perform daily activities to assess whether applicants are eligible for benefits and what those benefits will be.
  - Whether to allow beneficiaries to hire or pay relatives as providers. Doty et al (2000) report that findings support the option of hiring family members as providers because the data indicates that, on average, family providers are more likely to provide a higher quality of service than unrelated workers. Also, building the resources of families is likely to lead to improved quality of life outcomes for the relative receiving care. However, concerns persist (eg risks associated with undermining natural relationships, increasing the dependency between the carer and the person receiving care, and providing opportunity for abuse or over protection).
  - The design and implementation of appropriate systems to assist consumers to manage their own funds and to assist and protect them in employing workers (eg WorkCover insurance).
  - The requirement to establish cost benchmarks and payment rates, as well as a system to assure the quality of care provided.
  - The requirement to provide some assistance to help beneficiaries carry out their management tasks of recruiting, training, supervising, disciplining, and paying their workers.
  - The advantages of expansion of the model to incorporate crisis response for individuals considered 'at-risk' or with urgent, high or complex needs.
- *Service brokerage* - while most systems utilise the traditional case manager or service coordinator to assist people in utilising brokerage funds, the role should be defined to include teaching people and their networks about the resources and choices they have; helping to develop their budget; assisting to negotiate contracts; and monitoring to ensure that people's choices are being honoured and to assist if changes must be made.

- *Person centred planning* - what people want and need requires change within service organisations and communities; the care assessment and planning process can be designed as a tool to facilitate change. In addition, regular review of an individuals support arrangements are important in predicting and responding to changing needs across the lifecycle, allowing for early intervention if problems arise. As few staff as possible should be involved with assisting the individual to plan their supports, and consistent and ongoing relationships between the service coordination staff and the individual are important.

- *Individual funding packages* – while individual packages allow for more tailored responses to individual needs, the benefit is lost if services simply group people with similar profiles together or accommodate them within an existing service. Problems include accurate assessment of individual need, the capacity of services to cater to people with highly specialised or complex needs, the changing nature of individual need over time and the capacity of administrators to monitor outcomes (Community Services Commission, 2000). The importance of administrative separation of housing and support services has also been identified (Hulgin et al, 1996) in order to decrease vulnerability of the consumer to funding changes and other pressures affecting the provider, and to increase the ability to change agencies if desired.

- *Safety-net support* – the capacity to provide appropriate back-up support (eg to counter a change in the daily routine of a family member with a disability that impacts on care requirements, forcing significant changes in other family members' routines) or an avenue of return to a 'safe-haven' (eg if a new residential arrangement were to break down) is important in decreasing long term reliance on more formal, intensive forms of service.

- *Assistive technology market development* - coordinated approaches are required to ensure a strong market in assistive technology that will drive innovation, availability and reduce costs. A part of such a system would be a large-scale approach to coordinating agencies providing assessment and advice in relation to technology or making information about products available to prospective purchasers.

- *Self-directed employment initiatives* - access to employment provides greater independence and economic resources for people with a disability, potentially leading to reduced dependence on formal services and reduced reliance on informal carers and families. While the bulk of employment opportunities for people with disabilities will continue to come via the mainstream labour market, as an adjunct to this, common strategies to promote self-directed employment include (adapted from Nuefeldt & Albreight, 1998):

  - Creating awareness amongst people with disabilities as to the possibilities of becoming economically independent (eg entrepreneurial cooperatives, centres and services, working with vocational rehabilitation services, workshops etc).

  - Providing technical skills training for specific types of work and business management and entrepreneurial skills training (small business start-up and support services for people with a disability).

  - The establishment of small business advisory services for people with a disability who wish to become self-employed, and a national program of work-based personal assistance for people who are self-employed. This may include a pilot small business incubator catering for the special needs of people with a disability.
  - Providing financial support through loans or grants programs (eg the Self-Employment Assistance Project in Canada provides 52 weeks of income support, eight weeks of business training, access to micro-loan funds and ongoing consultation services). In Australia, benefit arrangements could be amended to allow registered job seekers eligible for employment assistance and subsidies such as workplace modifications to be eligible to receive the same assistance if they opt for self-employment.
  - Providing material support (including equipment, premises or raw materials to aid business development) and marketing assistance (including market research and support).
  - Encouraging home-based work arrangements (where appropriate) by assisting in negotiating with employers and providing practical advice for workers with disabilities who work or want to work at home. This might include overcoming isolation and exclusion from co-worker support and informal workplace communications, promoting professional development and advancement, and/or acquiring assistive technology (such as specialised keyboards, voice recognition software, screen reader software etc - large employers will often provide equipment and reimburse costs associated with technical support or operations, but smaller employers often don't and the costs fall to the employee).
  - Development of a resource that offers best practices and other suggestions for employers, unions, policymakers, researchers, organisations of persons with disabilities and agencies that provide job search and other employment supports to persons with disabilities. This should target younger job seekers as well as people who have a career history and established skills base.
  - Recognising the impact of rural and remote locations on employment assistance models. A recent Commonwealth study identified related three funding principles: funding should recognise the high cost of operating in rural and remote locations; funding should be appropriate to circumstances of rural and remote locations; and funding should promote viable, efficient and innovative services.

- *Access to generic services* – in the same way that the general population use a variety of services and resources to maximise independence, so should people with disabilities. This includes:
  - Increasing access to childcare services through cross-referral from family support and early childhood intervention services. Access to after school hours care, weekend care (Family Day Care) and the newly established in-home care service option could provide alternatives to CSDA funded respite services for some families.

  - Health services should adopt a lifespan approach that recognises the progression or consequences of specific disabilities. For example, regular health screening should be implemented to promote general wellbeing. Adults with intellectual disabilities and their carers need to receive appropriate and ongoing education regarding healthy living practices in areas such as nutrition, exercise, oral hygiene, safety practices ad the avoidance of risky behaviour such as tobacco use and substance abuse.

  - Adapting public transport services by initiating local action through bringing together private and community transport providers to form working relationships. Often a local facilitator will be required to achieve this, one who has the ideas and ability to bring local people together to discuss problems, investigate options for service development, who is not seen as 'captured' by an operator or sector, and who understands the regulatory and business environment and the needs of people with a disability. Effective solutions achieved through local cooperation include such simple things as re-directed public transport routes and 'hail and stop' bus systems.

- *Services for older people* - criteria for effective delivery of services to older people with disabilities include provision of choice and individualised planning, maintenance and strengthening of social networks, support for participation in the community, maintenance of skills, opportunities for self-expression and sense of self, and promotion of health and a healthy lifestyle (Bigby et al, 2001). This entails, among other things, removing the distinctions between day, residential and leisure programs, and accessing activities available from generic community leisure or aged care services as well as the disability day support service system (in many instances, to gain access to such services requires additional supports at either an organisational or individual level) (Bigby et al, 2001).

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