



ADVOCACY



POLICY



COMMUNITY

DEVELOPMENTAL DISABILITY *wa*

Submission to the Legislative Assembly Community Development and Justice Standing Committee

Inquiry into Accommodation and Intensive Family Support Funding
for People with Disabilities

January 2014

Developmental Disability WA (until January 2014 known as Developmental Disability Council of WA Inc, or DDC) welcomes the opportunity to make a submission to this inquiry and to comment on the issues raised in the terms of reference. Included in our submission are comments which a number of our members have asked us to incorporate with ours. A number of our members have also indicated they appreciate the opportunity to make a submission on this inquiry directly to the Committee. Developmental Disability WA would be very pleased to facilitate an opportunity for the Committee to hear directly from our members, and on behalf of the Disability Coalition of WA we extend a formal invitation to the Committee to hear evidence from a range of people with disabilities and their families and family carers in a specially organised forum.

1. ABOUT DEVELOPMENTAL DISABILITY WA

Developmental Disability WA is the peak advocacy organisation in WA for people with developmental disabilities and their families. We are a not-for-profit organisation which has been a leader in the disability sector for over 25 years.

Developmental Disability WA began in 1986 as an organisation supported by Activ. Our purpose was to provide a representative voice for a number of organisations which were providing services to people with developmental disabilities and their families. The organisations found that they had in common a number of concerns, issues and interests relating to the support, services and opportunities available to people with disability, in particular people with high support needs.

Developmental Disability WA is a community of interest with a broad membership of people with an interest in advancing the rights and needs of people with developmental disability and their families. Our membership includes: people with developmental disabilities and their families (our primary membership base); a range of disability support groups; various professionals working with people with developmental disability and their families; and a number of funded specialist disability service provider organisations. We currently have over 800 members, building on a membership last year of around 500, and our membership is increasing steadily as we offer a range of advocacy opportunities for individuals and families, support groups and organisations.

Developmental Disability WA works to create lasting positive change by:

- supporting people with developmental disability and their families to have a strong voice;
- partnering with others to develop more connected and inclusive communities, and
- influencing government and other decision makers

We provide a range of resources, information, skills and education opportunities such as workshops, forums and training to thousands of people throughout Western Australia. Each of these are developed in partnership with our members and stakeholders. Developmental Disability WA also engages in various capacity building and community development projects, again in partnership with our members and stakeholders. We are also strongly involved in State and Federal sector and policy development initiatives.

Developmental Disability WA's primary income is funding for systemic advocacy by the State Government through the Disability Services Commission. We receive additional small funds from membership fees and donations, and some of our capacity building and community development work is funded through time limited project grants.

ONGOING ADVOCACY ON FUNDING FOR DISABILITY SUPPORTS AND SERVICES

Developmental Disability WA has a long history of campaigning to raise issues relating to unmet need for specialist supports and services for people with developmental disabilities and their families. In 1995 we launched the statewide *Welcome Home* campaign in response to the crisis being faced by many people with developmental disabilities and their families in Western Australia who were looking for accommodation services but for whom funding to secure those services were not available.

In 1998, with many families still describing their situations as being in crisis, Developmental Disability WA sponsored the National Council for Intellectual Disability's national *Time to Care* campaign. This campaign was to address the critical shortage of support services for people with intellectual disabilities throughout Australia, which as well as accommodation, encompassed a broader spectrum of needs that were not being met, including respite, attendant care, early intervention, therapy, employment, day activities, independent living training, community access, day services, recreation and advocacy. As part of this campaign in 1998 Developmental Disability WA also set up the Politician Adoption Scheme to bring to the attention of politicians of all sides, from both State and Federal Parliaments, to the critical lack of services and support for people in their electorates and the wider community. The Politician Adoption Scheme continues today.

In 2001 the Time to Care campaign continued under the auspices of the Disability Coalition WA, an informal alliance of peak and representative groups in Western Australia - Carers WA; CASA; Developmental Disability WA (formerly DDC(WA)); National Disability Services (WA) (formerly ACROD (WA)); People with Disabilities WA; and WAAMH (the WA Association for Mental Health) – and was supported by many other service provider agencies. These campaigns have been recognised as contributing to sustained increases to the funding made available in the disability sector, which in WA were at comparably higher levels than in other States.

In 2011 the formalisation of a national alliance between people with disabilities, family carers and disability service providers lead to the first national, professional campaign behind a very specific systemic solution to the national problem of unmet need for supports and services for people with disabilities and their families – the National Disability Insurance Scheme. In this year the Australian Federation of Disability Organisations (AFDO), Carers Australia and National Disability Services came together and formed the *Every Australian Counts* campaign. With a campaign coordinator in Western Australia, this campaign provided a new opportunity for Developmental Disability WA to maintain its advocacy on unmet need for specialist supports and services in a very focussed way and in support of a very specific solution. We have been a proactive and consistent supporter of the campaign, including being part of the Western Australian campaign committee. Developmental Disability WA is also a member of the WA NDIS My Way Reference Group. In these capacities, we have hosted, supported and promoted numerous events to assist people with disabilities and their families gain information and ask questions about these key developments. Our targeted participation via the *Every Australian Counts* campaign and our

participation in key policy forums has enabled the organisation to shift its focus into areas of unmet need for other support for people with disabilities and their families, including issues relating to school education and family leadership.

While there is great optimism about the introduction of a universally accessible care and support scheme for people with disabilities and their families, there is also recognition that it will be some time before such a scheme is fully operational. A two year trial of the National Disability Insurance Scheme in the Perth Hills area and of the state government's My Way model in the Lower South West and Cockburn-Kwinana is set to commence in July 2014. A review of the impact of the two models is set to inform the development of a final model for a universal care and support scheme in Western Australia. After the model is finalised, it is possible that its implementation will be introduced in a staged manner. In the interim, many people with disabilities and their families will continue to live with the effects of unmet need for disability supports and services.

SCOPE OF THE INQUIRY

Developmental Disability WA welcomes the opportunity to provide input to the Committee on the issue of funding for critical disability support services. Despite recent significant policy developments in the long-term systemic response to this issue, unmet need for these services continues to be a real challenge for many people with disabilities and their families.

The issues canvassed in this inquiry have been extensively canvassed in numerous inquiries over time at both State and Commonwealth levels, and most recently via the Productivity Commission inquiry leading to the National Disability Insurance Scheme. The launch/trial of the NDIS is commencing in WA in July 2014, and this year there will also be trialling of My Way sites. The outcomes of these trials after two years will determine what the systemic response is, going forward, in terms of meeting the increasing demand. In the interim we recognise that the issue of unmet demand will continue.

In this context, Developmental Disability WA would welcome feedback about how the Committee believes it will use the information to influence change, and in the context of current and future developments. We believe that there are two key ways in which the Committee could seek to have a positive influence as an outcome of the Inquiry. The first is to call for significant funding increases for disability supports and services to continue to address unmet need until the resolution of the final NDIS/My Way outcome. The second is to use the findings of this Inquiry to assist the Committee in evaluating the outcomes of the NDIS and My Way trials to ensure that the ultimate outcome of this process is something that is going to address the issues raised here.

We would recommend to the Committee that it is important to ensure that NDIS/MY Way respond to these fundamental issues of increasing demand and unmet need and potential remedies.

While Developmental Disability WA generally endorses the Terms of Reference of the inquiry, we were curious about the decision to restrict the inquiry to Accommodation Support services and Intensive Family Support specifically. We respectfully suggest that the scope of this inquiry be broadened to include all funding and support, if the intent is to learn more about the existing systems in order to more adequately manage these types of supports (formal funding arrangements) into the future. For example, if people's post-

school needs are not addressed effectively through Federal employment support or Alternatives to Employment, then this can have flow on effects that impact on demand for IFS or Accommodation support. Furthermore, whether or not there is comprehensive investment in early intervention strategies has a flow on effect by increasing the need for 'urgent and critical' supports. The issues of unmet need and the processes for allocating funding are across the board and not limited to IFS and accommodation services. IFS and accommodation services need to be considered in the context of other developments which seek to support people earlier as a form of early intervention.

While the system currently delineates between different programs, there is a shift away from allocating funding according to specific programs and towards a more holistic assessment and funding response. This will be a feature of both the NDIS and My Way, and we understand that it is DSC's intention to extend this approach to CAP.

We would also encourage the Committee to extend the scope of its inquiry to include examining the important role of earlier supports in mitigating against people's situations becoming 'urgent and critical'. Despite recent investment initiatives to actively support earlier planning through Community Living and Family Living, the current system funding system is predominantly focussed on supporting people when their needs become 'urgent and critical', at which time both the financial cost of support and the emotional impact on people with disabilities and their families is likely to be greater. In the interests of long term sustainability, we believe it may have been helpful to include questions about support for individuals and families in a more general sense, in addition to questions about formal support structures such as the two funding programs referred to in the terms of reference. In this context, we have raised issues pertaining to formal early interventions such as Community Living and Family Living as well as to other development initiatives that support capacity building, including family leadership, peer support, self-advocacy and advocacy.

We have made reference to other funding programs above, and believe these and others should be considered in the context as those referred to in the terms of reference.

2. THE LEVEL OF UNMET NEED

Despite the consistent growth in funding for disability supports and services, there has continued to be a gap between the level of need and demand for disability supports and services and the level of funding available to meet that demand. This is a key reason why Developmental Disability WA has supported the National Disability Insurance Scheme – as a means for ensuring that the level of funding for disability supports and services was based on need.

Gaining accurate measures of need is a complex process. Measures of need must not only identify the number of people that will require supports and services, they must also seek to anticipate the nature of that need during the course of a lifetime, recognising that people's need for supports and services can change over time. People's 'need' for disability supports and services during the life course is not simply an objective measure of their functional impairment. The type and level of support or services a person might need will be shaped by a range of things in their life, including the level of informal support available to that person and the sustainability of that support.

Statistics from the Disability Services Commission (DSC) demonstrate very clearly that the expressed demand for disability supports and services exceeds supply.

- In 2012/13, 1,911 people applied for disability supports and services through the Combined Application Process (CAP) and \$23.6 million was allocated¹. This is the key funding allocation mechanism, with a focus on providing supports and services to those who have identified as having an urgent and critical need. Only 39.4% of those applications were successful in securing new packages of funding. A breakdown by program area shows that:
 - 28.8% of applications for accommodation support were unsuccessful
 - 28.2% of applications for Intensive Family Support were unsuccessful; and
 - 41.7% of applications for Alternatives to Employment—were unsuccessful

The CAP not only captures applications for new packages of supports and services, it is also a key mechanism through which applications for increases in funding to respond to changed needs are assessed. The latest Disability Support Funding Bulletin indicated that only 32 people received funding for changed needs, but it does not indicate how many applications in regard to changed needs were made.

In addition to the traditional CAP funding for urgent and critical need, other packages of 'early intervention' support are also available via the Community Living Initiative (CLI) and the Family Living Initiative (FLI). The CLI and FLI were developed in order to provide more people with smaller amounts of funding earlier to assist people to plan and develop strong supports that could help mitigate against urgent and critical need. In 2012/13 \$4.2 million was allocated to 241 people across these two initiatives. These initiatives are important because it is widely recognised that high quality early intervention can assist in curbing higher levels of demand later on.

Data on unsuccessful applications is not a comprehensive measure of demand or of need. These figures naturally do not include people who did not apply because of past experience of unsuccessful applications, or because of advice that they would most likely not be successful because they are not 'urgent or critical' or other reasons.

As indicated above, one of the key reasons that Developmental Disability WA has supported the NDIS is that as an insurance model it seeks to ensure that the funding available for disability supports and services matches the demand in the community, and a key priority for the National Disability Insurance Agency (NDIA) is to ensure it has a clear measure of that demand now and into the future. These actuarial functions of the NDIA will be critical to the long term sustainability of this reform. The Productivity Commission has itself faced challenges in being able to adequately determine what the need might be in regard to the NDIS – testing assumptions about need and demand were to be some of the objectives of the launch/trial sites.

The Productivity Commission's key points statement on the NDIS state at point 4:

The main function (and source of cost) of the NDIS would be to fund long-term high quality care and support (but not income replacement) for people with significant disabilities. Everyone would be insured and around 410 000 people would receive scheme funding support.

¹ Disability Support Funding Bulletin; Issue 2 – September 2013; Disability Services Commission 2013

An indicator of people who state that they have disability or care for a family member can be found at the ABS Survey on Disability and Ageing. This is one of the most commonly referenced data sources in trying to grapple with measures of unmet need for disability supports and services.

- Just under one in five people (4.2 million people or 18.5% of Australians) reported having a disability in 2012.
- Of these 4.2 million people with disability, 3.7 million had a specific limitation or restriction that meant they were limited in the core activities of self care, mobility or communication, or restricted in schooling or employment.
- Of these 3.7 million people, 736,800 people reported a profound limitation; 654,700 reported a severe limitation; 641,300 reported a moderate limitation and 1,379,800 reported a mild limitation.

The same ABS report shows that in 2012 almost 2.7 million Australians identified as carers.

- Of the 2.7 million people, around 770,000 (29%) were identified as primary carers
- almost 75,000 carers were aged less than 15 years
- primary carers were significantly more likely to have a disability themselves, with around one third of primary carers having a disability (37%).

The report also states:

A person who needs assistance with an activity may or may not receive the help they require. Though most people needing assistance received at least some help (98%) more than one third reported that they did not receive the full amount of assistance they required (39% or almost one million people). This was an increase from 2009 when 36% of people with disability indicated that they did not receive all the assistance they needed. Generally, people were less likely to report their needs as being fully met as the severity of their limitation increased. For example, less than half (47%) of people with a profound core activity limitation reported their needs as fully met compared to 61% for all people with disability. This also represented a decrease from 2009 when 53% of people with a profound core activity limitation reported that their needs were fully met.

Within the NDIS and My Way, how and when need is expressed and to what level it is met will be important things to monitor. The great hope of these reforms is that they will provide access to support on an entitlement basis, closing the gap between eligibility and access – that once people are found eligible they will have access to support when they need it. With regard to the NDIS, the way in which ‘reasonable and necessary’ supports is negotiated is an area of interest for advocates as we observe the roll out of the NDIS in other states as we prepare for the WA trial. Of particular interest for Developmental Disability WA will be expectations on the level of informal support to be provided by families, and what support is also available to those families to provide the informal support that is expected of them.

The limits of measures of ‘unmet need’ and the importance of broader planning

Most conversations about measuring unmet need tend to focus on population based measures of functional impairment. What is often missed in these measures are the contexts in which people with disabilities and their families are living and the ways in which

various environmental factors shape the level and type of support. Two individual people living with the same functional disability can experience entirely different needs for supports and services based on a range of factors in their lives. Population based measures of 'need' often don't capture those elements of people's lives and so a range of underpinning supports and services that can support the capacity and resilience of individuals and families is often missed, with the likely impact of increasing people's risk of developing urgent and critical needs. Not surprisingly, it is this aspect of 'need' that our disability system is far less effective at responding to, in part because it does not sit comfortably within a formal service delivery structure. It is an area that Developmental Disability WA has become increasingly active in through a number of short-term project based grants through DSC. However, investments in this kind of work in Western Australia beyond the Local Area Coordination model have not been sustained or consistent over time. The Productivity Commission and the National Disability Insurance Agency have both acknowledged the importance of working at this level, and for comprehensive strategies which support that aspect of the NDIS.

There is also no doubt that the effectiveness of other non-disability support systems have a flow on effect on the nature of people's need for disability supports. Where people with disabilities have poor access to high quality services and outcomes in areas like education, employment, health and housing for example, this will have flow on effects to their demands for specialist disability supports and services. The inter-connectedness of people's needs was at the core of the National Disability Strategy and the *WA Count Me In – Disability Future Directions* plan. Many of these factors come together at the local/regional level, and so understanding what 'need' looks like locally is also relevant.

In the Concept Plan guiding its current Sector Development Plan, the DSC states that it uses a range of information sources to shape how it guides the 'growth and development' of the WA disability sector including various population data sources and CAP data on unmet demand. However it also acknowledges that 'decision making about the growth and development of the sector has been guided by a comprehensive and detailed plan for the sector'.

The Sector Development Plan, which is still being developed, was initially lead by the now disbanded Sector and Community Development Branch and was intended to provide a geographic/regionally based assessment of the current service system, current and future demand, and service gaps and areas of development. After an initial analysis of data, localised community consultations were undertaken to inform the process. We understand that in the early days of this plan there was an attempt to tap into multiple data sources to map demand/need by location/region.

3. THE ADEQUACY OF CURRENT PROCESSES FOR DETERMINING FUNDING SUPPORT FOR PEOPLE WITH DISABILITIES WHO LIVE WITH THEIR FAMILIES

Unlike other systems where funding is allocated on an eligibility basis, the CAP funding and other DSC funding programs are not definite or transparent and eligibility is not enough of a guarantee. This is consistent with the experience in other States, and again is a key driver behind the National Disability Insurance Scheme. Despite people being eligible for funding on the basis that they meet the criteria for application in the first instance, there is little to no transparency when it comes to the reasons for decisions on outcomes of assessment. A fundamental flaw in the current system is that the pool of funding available for the

programs referred to in this inquiry is limited rather than consistent with the need, the process of allocation has taken on 'urgent and critical' as the rationale for prioritisation of resources. As indicated earlier in this submission, this is a key reason why Developmental Disability WA has supported the NDIS – as a sustainable mechanism to provide a level of resourcing sufficient to meet the level of need in the community. Any system that from its outset bases its assessment and funding decisions on 'urgent and critical' need in an environment where most of that need cannot be met is inherently problematic and necessarily alienates and disenfranchises people who seek to access that support.

The inadequacies of the current CAP process have been evidenced numerous times at many inquiries – we know there are huge levels of unmet need, funding comes too late if at all, people are not getting enough support earlier, people feel they have to present the worst possible stories about them and their family in order to demonstrate need, they have reported feeling humiliated and distressed at having to do so, they feel they are in competition with others, and they are not confident about decision making and do not understand how decisions are made about who receives it, how was that decided, how much and why that amount.

Because the allocation is effectively based on 'urgent and critical' there are fundamental difficulties in the process being transparent. 'Urgent and critical' is not an absolute term that can be defined and objectively and consistently applied. In an environment with limited resources, it is inevitably a relative concept. For all of these reasons, it is difficult to devise a transparent process that individuals and families can understand and have confidence in. It also make adjudicating or appealing any decision difficult, and in fact there is no external appeal mechanism available to people.

The CAP utilises an independent panel to review funding applications and prioritise those applications according to 'urgent and critical' need. Unfortunately there is very little information available to the community about how the CAP panels work, how they assess the information that is provided to them, and what things guide their decision making. It is not clear why the Government does not go to greater lengths to provide this kind of information to the community. While this knowledge would give little comfort to those individuals and families whose calls for supports and services go unanswered, it might give people a broader understanding as to why current system works as it does.

"The Disability Services Commission engages an Independent Priority Assessment Panel to ensure these funds are provided in a fair and equitable manner through the Combined Application Process (CAP).

The Independent Priority Assessment Panel is a diverse group of highly experienced people from varying backgrounds. Each panel comprises a person with disability, a family member, a representative from a disability sector organisation, a consumer advocate, and a senior officer from the Commission."

Source: DSC website

An adequate process would be considered as one which ensures people get what they need when they need it. It would be sustainable, and would in our view invest in people earlier in order that 'urgent and critical' are better managed or better still, avoided. An ideal or adequate process would also be one which people understand clearly – that they know exactly how they will be assessed, that the assessments are transparent, that they believe all assessments are done consistently. An adequate process might have an avenue for

recourse or appeal against decisions, however in an environment where the funding is so limited this is virtually impossible.

We believe that a greater investment in early interventions may address some of the issues which result in families getting to the point that their demand for support later on becomes 'urgent and critical'. As one of our members stated:

"...parents have had to demonstrate total decline and dysfunction within the family unit before they are successful for IFS or accommodation funding. As a result the system focus is on management of extreme crisis situations such that the prevention of behavioural decline and the maintenance of the family unit are overlooked."

We acknowledge however to make an earlier investment it important not to compromise the level of support that is available to those in crisis. Again, this is a reason why we have supported the NDIS because of its recognition of the need for early intervention as a preventative measure, while also responding to critical need.

Any system for funding disability supports and services which neglects early intervention will increase the long term demands on it and will not be sustainable in the long term. With this in mind, the CLI and FLI have been welcome initiatives in early intervention in the sense that they are smaller levels of funding but allocated so that people can build good informal supports which they can sustain for longer, thus mitigating the need for urgent and critical support, which is funded via CAP.

Until recently, CLI and FLI plans were assessed and funded via a centralised process whereby an independent panel consisting of individuals and families, DSC staff and often a service provider who would review the plans for which DLI/FLI funding was being applied for, then make recommendations to the Director General. Recently, assessment and funding of CLI and FLI applications was devolved locally (through regional offices and LACs). It is understood that the key driver behind this shift was to increase localised decision making, which is one of the key principles of the State government's My Way alternative to the NDIS. We are currently awaiting responses to some specific questions on how this localised assessment and funding will work, but we understand that each region now has its own funding allocation for CLI and FLI and that within each region applications for CLI and FLI will be made to the local LAC offices where they will be assessed and funded.

In principal, Developmental Disability WA, along with many other individuals, families and organisations, strongly supports local decision making, particularly on the basis of the value of local knowledge, intelligence and relationships in developing good plans and supports. However, we do believe that there might be some challenges in devolving resource allocation decisions to the local level. For example, we are conscious that there might be potential tensions when the decision maker is so close to the local community and the individuals and families making applications.

We are also concerned that with plans being assessed at the local level, there is a possibility that there will be greater pressure on CLI/FLI to be directed to local individuals and families who are in critical need. And with any limited funding pool, there is the possibility that plans will be scaled back so that local funding pools can be stretched further.

We have been informed that where people elect to have an organisation manage their funding, their CLI and FLI includes an amount for administration. If this is correct we are concerned that this may place increased pressure on an already limited pool of funds.

Given the changes to decision making in these areas we have asked the Commission to provide information so that we are also better aware and informed.

4. THE NATURE AND EXTENT OF PLANNING REQUIRED TO MEET INCREASING DEMAND FOR THESE SUPPORT SERVICES IN WESTERN AUSTRALIA IN THE FUTURE

In terms of the nature and extent of planning required to meet the future need in WA, we believe it is important to distinguish between two forms of planning – planning for meeting the need for formal services and supports such as those mentioned above, as well as planning for strengthening the capacity of people with disabilities and their families and family carers so that they are able to be better supported in how they provide their care and support. This point was initially raised in the discussion at section two about the limits of population based measures of need.

We believe a greater investment toward planning for strengthening capacity for individuals and families and family carers would contribute to the long-term sustainability of any of the formal support system. As indicated above, we believe this needs far greater strategic investment in Western Australia.

This was also recognised by the Productivity Commission who distinguished between the different tiers of services – both formal service provision and informal community based supports.

An example of informal community based supports would be the Positive Behaviour Support Committee which Developmental Disability WA has been involved in over the last two or so years which included work in the elimination of restrictive practice. Our work here involved a family mentoring program, Side by Side, where families with a child who demonstrated what can be seen as challenging behaviour, worked with another family who had been down that road or were still going down that road. The families ‘mentored’ families, worked together within the community and we had overwhelmingly positive feedback. Word of mouth has led people to approach us about the possibility of them becoming involved in the program however for now this is on hold as our grant has ended and we are seeking alternative sources of funding. Developmental Disability WA and a number of other organisations also held workshops around Western Australia, in regional and metropolitan regions, on the elimination of restrictive practice. These were well attended by families and support workers who found the workshops and resources extremely valuable in providing them with the skills to support people with challenging behaviours.

Developmental Disability WA has also done a lot of work in education, under the banner of Learn and Grow. Learn and Grow involves many things but importantly helping families feel they can make the right decisions and choices for their child and their family in terms of education. Learn and Grow includes self-advocacy workshops, forums, discussions and practical resources. It involves skilled and experienced education experts and facilitators, and families with personal experience, all of whom bring a wealth of knowledge and support

to the families involved. We have also been working with a range of family leadership networks on understanding, mapping and building capacity to support family leadership.

These types of early interventions can often help individuals and families avoid their domestic situations, family lives, turning to crisis.

We do not suggest that investment in these and other early interventions will completely remove the need for support at 'urgent and critical' point, nor replace the need for many other formal supports. However we feel very strongly that building capacity at individual and family level is a sound social and economic investment for the State and Commonwealth. Consistent support for the development of self-advocacy, family leadership, individual and systemic advocacy and support groups come at comparably lower economic cost to Government than do 'urgent and critical' support funding. Support groups also come under this category of capacity building, as they provide enormous support to individuals and families and networks throughout our State, at very little cost.

We would acknowledge the vital role of Local Area Coordinators in Western Australia who have become a model for support with the introduction of the NDIS. We share concern with others as to whether as a State we have relied too heavily on LAC's to support individuals and families in the sector, and would caution against placing further strain on their already enormous roles. We believe that there are significant networks, relationships, and experience beyond the formal services structure that could be better utilised and invested to work with individuals and families. Over the last two years, Developmental Disability WA has had the opportunity to administer a small grants initiative for disability support groups, which as mentioned above, provide enormous support throughout our State.

We have said that an adequate system would be one in which people have access the support that they need when they need it, but in planning we also have to recognise that there are going to be significant limitations on the ability of any system to meet all demands on it in a sustainable way.

In terms of planning for the formal service delivery sector, we have made reference to the Sector Development Plan which is currently being developed. Developmental Disability WA is on the Sector Development Plan Reference Group. Planning for the future must not only look at sustainability in terms of levels of funding, but must also look at the range of things that make a services sector sustainable and responsive. Workforce needs for the disability services sector have long been a key issue, as has been access to housing. The development of the sector to respond to the diverse needs of people with disabilities and their families must be an ongoing process.

5. CONCLUSION

Developmental Disability WA welcomes the opportunity to make a contribution to the inquiry. It comes at a critical point in time as we prepare for the trial of NDIS and My Way as systemic responses to the long held issue of unmet need for funding for supports and services. The completion of the trial, development of a final model, and its subsequent full scale implementation is still some time away and these issues will continue to impact on the lives of people with disabilities and their families in the interim.

Developmental Disability WA believes that unless and until we resolve the gap between the level of need for supports and services and the level of funding available then we will continue to see significant levels of unmet need and frustration by people with disabilities and their families about the adequacy of assessment and funding processes. But we also recognise that funding and formal support services are only part of the picture and that in order for us to ensure formal service systems are sustainable in the long term, we also need to look at how well we are supporting people with disabilities and their families to have strong informal connections and supports. We must recognise that for a great many people there will ultimately be a need for a formal service delivery intervention at some time and we must ensure that our system is more effective at allowing people to have those needs met in a timely fashion.

We have concerns that our current system tells people with disabilities and their families that they should seek out formal supports and services as a last resort only and that informal and community based connections must play a greater part in meeting needs, without necessarily investing in empowering and supporting people to build and maintain those networks and to develop as leaders for change in this sector into the future. Developmental Disability WA has had several opportunities to start testing some ways of working in this space with the support of DSC, but we believe a more specific focus on this kind of work is required.

To complement our written submissions to this inquiry, Developmental Disability WA and a number of other organisations are conducting a survey of people with disabilities and their family carers on their experiences in relation to these matters. The timing of this inquiry over the Christmas break was difficult for individuals and families, as well as in relation to staffing of organisations.

Our survey also looks at the broader scope rather than just the two programs specified in the terms of reference in this inquiry.

The survey will be concluded by 5th February 2014 – we hope we will be invited to give evidence and we would expand on our findings and table a report on the survey in that forum. As indicated earlier in this submission, members of the Disability Coalition of WA extends an invitation to facilitate an opportunity for the Committee to hear directly from people with disabilities and their families on the matters raised in the inquiry and in our responses.
