In preparing this submission I believe that we need to give some personal background to provide some idea of what we have experienced in dealing with a disabled member of our family. This may provide some credence to and rationale for our answers to some of the questions.

Personal Background.

Our daughter Debra was born in 1968 the third child in a family of four. Within days of her birth she was diagnosed as a Down syndrome baby and we were informed immediately.

At that time there was very little written about Down syndrome and virtually no services or support groups. The only service we could find was Noah’s Ark toy library and we used that as a support group and a means of gaining encouragement.

Integration was being discussed at a state government level but, with no practical support for the scheme at a government, education department, or school level.

Our daughter attended a local kindergarten only after a lot of insistence from us and she was the only child to have an intelligence test that was required as a precondition of being accepted into the kindergarten.

Our daughter attended the kindergarten for two years instead of the usual one and then was accepted into the local primary school, only because a dedicated teacher there, who had taught our elder children asked if she could teach Deb in her normal grade. She attended this school for two years with the same teacher teaching her and she learned to read and write in that time. After these two wonderful years she had to transfer to a Special School as the dedicated teacher gained promotion and left the school and there was no other teacher who would take on the task of teaching a disabled pupil and there were no support services for classroom teachers. Thankfully that situation has changed dramatically in the intervening years.

The experience at a Special School while providing reasonable education did not extend our daughter as she should have been extended in reading and writing but there was a lot of emphasis on social skills and independent living skills like cooking, shopping and house keeping.

After special school Debra entered the workforce in a (Sheltered Workshop) now called Supported Employment, where she has been for the last 25 years.

We attended the Parents and Friends meetings to give and gain support with others in a similar position. This provided valuable information about future opportunities for social activities as well as the possibility of supported housing.

When we learned that any opportunity of a place in a house was very low we decided to look at providing accommodation for her ourselves.

We had been wrestling with this problem of housing of our daughter for a number of years, as she trained through the Uniting Church “Genesis” program in 1997 in Blackburn. During that 20 week live in course she learned to live independently of us. She then lived in rented accommodation for 2 years before we decided to buy a house for her. The full story is recorded in a book that we have written, “Letting Go. The Story of Deb.” ISBN 0 9756792 0 1,

Prior to the establishment of Special Disability Trusts many parents, us included, had used a Discretionary Trusts for their disabled people. In our case we used some of our Superannuation capital to buy a house for our disabled daughter. This penalized us for 5 years as far as Centrelink benefits were concerned; it was seen as a gift. After two years of some Centrelink benefits the rules were again changed so that Centrelink could consider the assets of a trust as belonging to the appointor. So we now had our gift back again and we had to bear the loss of a significant part of the pension, while still providing housing and support to our daughter.

This situation was experienced by many parents as they tried to provide long term care and accommodation for their disabled people. Fortunately the then Senator Kay Patterson became aware of the situation and encouraged the amendments to the Social Security Act of 1997 to enable parents and carers of severely disabled children to set up Special Disability Trusts for the people in their care.

We set up a SDT for our daughter and transferred the house into it as the major asset and this operated well for another year before we had to sell the house and accommodate our daughter closer to us in a unit.

The operation a SDT is controlled by Centrelink and the initial assessment of our daughter presented problems as the instrument to assess her was also used to assess people for a Carers Allowance. The first attempt resulted in failure to qualify in spite of her Down syndrome condition. Some of the rules of operation had to be modified by a later act of parliament as they were too punitive. (Taxation, maintenance of property and expenditure for social activities.) This highlights for me the need to monitor any designed scheme very carefully, especially as it begins to operate.

Debra’s independent living skills have declined with age and she now needs much more basis support from two carers on a weekly basis and for help from the local council which provides for housekeeping and cooking meals on a fortnightly basis. This ensures that she has help with most of the household tasks and leaves us independent to monitor the situation and provide support where necessary.

National Scheme administered locally.

My belief is that the scheme should be National but administered locally, and by that I mean the Federal Government sets up the scheme, collects the revenue and then disburses it to local government for them to administer and report.
If this were achieved it would cut one layer of bureaucracy out of the equation, ie the state governments.
The local councils are much nearer the clients and already provide many services for disabled people, meals on wheels, home help, health services etc. It also helps to address some of the situations experienced by remote communities.

Who should be in the new scheme and how could they be practically and reliably identified?

People with genetic abnormalities should automatically be included after the diagnosis is made. This should be the only qualification as paper assessments are notoriously unreliable, especially for those mildly affected. (Our experience!)

How could people with disabilities or their carers have more power to make their own decisions (and how could they appeal against decisions by others that they think are wrong)?

Funding should be assessed on demonstrated need. Expenditure of the funds should be in the hands of the disabled and or carer with reporting to the funding body on an annual basis.

Appeals against unfair decisions should be subject to an appeal process similar to the Social Security appeal process. First level is to an independent expert for their assessment then to an Appeals Tribunal and finally to an Administrative Appeals Tribunal. It should be exclusively designed to exclude lawyers and an open and easy to negotiate process so that individuals are encouraged to appeal if necessary.

How should the amount of financial support and service entitlements of people be decided (and by whom)?

This would need to be negotiated with clients, carers and funding body. Perhaps initially some sort of indicative funding table could be established.

What kinds of services particularly need to be increased or created?

There are many people with mild disability and given some training and encouragement can be helped to live an independent life relieving parents and carers of a lot of the responsibility. There is one such training scheme in Victoria called Genesis, run by the Uniting Church agency, Harrison Family Services at Wantirna. This would be an excellent program that should be replicated across all states. Parents of disabled people could be encouraged to help such children to participate and become more independent.

Are there ways of intervening early to get improved outcomes over people's lifetimes? How would this be done?

There are already many early intervention groups and programs especially for birth and genetic defects. These should be encouraged to expand and parents given the opportunity to use these services as they see the need. Parents would purchase the services from their allocation of funds.

How could a new scheme encourage the full participation by people with disability and their carers in the community and work?

Part of the obligation of funding should be the expectation that the person receiving the funding participates as far as possible in some work or community building program as much as they are able given their level of disability. There would need to be a wide range of work and activities that could be accessed to cater for the level of the disability.

What should be done in rural and remote areas where it is harder to get services?

See the comments under National Scheme administered locally.
In some of these cases it would be an advantage if increased funding was applied to enable the purchase of services that would be inherently more expensive due to the remote location.

How could a new system get rid of wasteful paper burdens, overlapping assessments (the 'run around') and duplication in the system?

Keep as much as possible of the design and administration out of the hands of centrally administered bureaucracy. It is evident in dealing with the Special Disability Trusts that those that designed and administer the scheme have very little concept of what it is like dealing with the day to day difficulties of a disabled person. If they had any notion of what parents and carers of the disabled went through on a regular basis they would design a radically different program which was much more user friendly!