Disability Care and Support inquiry
Productivity Commission
GPO Box 1428
Canberra City ACT 2601

Background

Our son has a severe intellectual disability - a rare x linked disability resulting in limited language and severe behavioural problems if not addressed with understanding.

We have self managed our son's Community Participation funding for the past two years.

Before that time funding was held by local disability service.

The move to self managed has changed our son's life and our lives dramatically.

We no longer have a son who is stressed or who self mutilates -
remember behaviour is language!

Our son is now part of his local community and is greeted and welcomed by locals everywhere he goes. He feels good about himself.

Service Issues

The service tried their best but did not understand our son at all.
Their files were thick with behavioural incidents and our son was had gained the title of "their hardest client".
Most staff went on his reputation and approached our son with fear.
Support for our son was day based - three days per week - at one point due to behaviour they had two support people with him - how this looked to local members of the community is anyone's guess.
Two support staff did not prevent an incident when he was lost in a National Park and was only found late that night sitting on a cliff edge - found only due to the efforts of his old school teacher.
Two minders did not prevent this.
You can see from the above that supports were tried & failed & did not meet the needs of our son.

Solution

We heard about self managed.
We had nothing to lose so plunged in.
We advertised for support staff and attracted amazing people.
Each person saw the ability and not the disability.
All support persons have welcomed our son into their lives and the lives of their family and friends.
All staff who support our son are still with us and enjoy the challenge of support.
We are empowered as parents as we know what works for our son - we do not need a service thinking up solutions - we do not need meeting after meeting.

We found the cloak of service provision weighed heavily on our lives.
Our son had been assessed to death - behaviour plans written -each day copious OH & S notes written up to cover service fears - We had to change this,

Self Managed CPP has been amazing for our son and for us!

Respite Issues

Our respite support in the past had not been ongoing.
Our needs were known and documented.
We waited each year with the fear that respite support would not be ongoing.

We heard of an opportunity to get recurrent respite funding - the catch was we had to bear our souls to a room brimming with service providers.
We found this experience extremely stressful and degrading.
They knew our need - but we were put in a position of having to **compete** on need for some recurrent respite funding.

Solution

We would suggest that this type of assessment cease.
ADHC has all the documentation they need - get someone with experience, understanding and empathy to make one visit to a family.

If this cannot be done then you have serious flaws in the way you assess the needs of families, putting one families stress against another's is appalling.

Disability does not go away – it is constant for the rest of our lives.

We need guaranteed ongoing support

Conclusion

Disability support in a case like ours should be an entitlement - not a begging situation.
We want the right to choose.
We know what works.
We want the right to be respected and trusted - I know where every dollar that has been spent from our son's CPP funding and I know what our $ contribution as a family has been.
I know I am accountable for funding and I know how to show this expenditure and get the best outcomes for our son and our family.

So as a government body you need to respect parents.
Give us choice.
It is all about an ordinary life.
My son does not need the title of client as his career in life.
He just needs good supports to take part and be a valued member of our community.
Some parents choose not go the way of service based segregation, day services and congregation
Some do - give us choice!

I would eventually like to move to direct funding for all our support needs.
We have a Special Disability Trust Fund set up.
This Trust deed has annual auditing requirement.
We could save 20% admin dollars collected by the services holding our funding dollar. This could provide more support for our son

We are well and truly over the service provision model - it has been found to be wanting in so many areas.