Establishing a user led Disability Support Organisation -

from idea to realisation

The journey towards and learning from the establishment of Community Disability Alliance Hunter, an independent, user- led disability support organisation.

May 2013

The Community Disability Alliance Hunter (CDAH) strives for an inclusive and just society where people with disability have voice, choice, control and active citizenship through social, economic, cultural and political participation.

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# Executive Summary

This resource is the result of our experiences and learning over the past 7 months as we worked to establish a Disability Support Organisation in the Hunter, the launch site for the National Disability Insurance Scheme (NDIS) in NSW.

The aim of this resource is to provide some information and assistance to other groups of people with disability, families and allies who also want to make sure that the opportunities suggested in the Productivity Commission’s report into Disability Care and Support will be delivered to people with disability and their families.

A user led Disability Support Organisation, like the one we are about to incorporate, is run by and for people with disability and their families with the aim of helping *“to get the support we need to live the lives we choose”.* It is an independent, collective voice committed to full inclusion and active citizenship.

# How to use this resource

This resource is written for people who want to set up a user led organisation to provide people with disability and families with some of the supports people will need to get the most out of the changes happening with the introduction of the NDIS.

There are two parts to the resource. The first part tells the story of our journey.

The second part is a collection of resources that you might find useful in creating your own organisation.

Finally, you can contact us on [www.cdah.org.au](http://www.cdah.org.au)

Good luck with establishing your organisation.

# What was happening – or what got us started

“The current disability support system is underfunded, unfair, fragmented, and inefficient” (Productivity Commission)

In 2011 the Australian Productivity Commission released its report into Disability Care and Support. The Commission recommended the introduction of a National Disability Insurance Scheme, a whole new way of delivering supports and services for people with disability and their families.

In the report the Productivity Commission introduced a new type of agency called Disability Support Organisation (DSO). The Commission envisaged the main roles of the DSO would be to act as an agent for a person with a disability and provide a range of supports, including:

* Personal planning services and individual guidance
* Linking people to community
* Assembling ‘packages of supports’
* Undertaking administrative tasks for people using self- directed funding
* Providing data to the National Disability Insurance Agency
* Providing innovation in the coordination of services

In August 2012 the NSW State and Federal Governments announced that the NDIS would begin in the Hunter region in July 2013. In December 2012 both the NSW State and Federal Governments agreed on the roll out of the NDIS across the rest of NSW.

With so much activity concentrated in the Hunter and with so many changes underway, it was a good time to think about how the voice of people with disability and families would be heard and how our interests could be protected and promoted. We wanted to make sure that people with disability and families could get the best outcomes from the NDIS.

# Our story

## 1. Building Interest: leading up to the NDIS forum

Like most things, our journey started with a few people who had energy and connections.

“This is an exciting time for local people with disability and their families. We’ll be among the first to experience what it can mean” (Linda Hughes)

Mind the Gap- Disability Matters, was a newly created organisation committed to redressing the many gaps experienced by people with disability and to bring about a community where people with disabilities enjoy the same rights, opportunities and freedoms afforded to the broader community.

In Control NSW is a loose network of mainly advocacy organisations and a few individuals.

Family Advocacy, one of the key drivers in In Control saw the emerging opportunities and started connecting with people.

So the ideas of building partnerships and working together have been central to our work right from the beginning. These two things have been some of the most important learnings from our journey.

With the backing - and some financial support – (more about money later in the All about Money section) from In Control, NSW a local event was organised for people with disability, family members and service providers. We were lucky; there was a fair bit of interest in the community and some of us knew how to attract media attention. We used our contacts and got a fair bit of local media, both print and radio. It certainly helped getting the word out.

More than 230 people attended the “NDIS in the Hunter: Getting in Control” forum. We asked people with disability and family members speak about their own experiences of making more choices and taking control. A representative from the National Disability Insurance Agency talked about the NDIS and the work ahead. In the afternoon, over 100 people with disability and family members stayed on. We looked at the experiences of user led disability support organisations in the UK and talked about how we could strengthen the voice of people with disability in the Hunter.

“We begin with the assumption that people can make their own choices” Dougie Herd,

We discussed whether there was enough energy and ‘appetite’ to set up of our user - led, disability support organisation. We were not yet sure what that might look like or how we could make it happen, but 30 people put up their hands and wanted to be involved. This is really when our journey started in earnest.

### Key things we learned in building interest:

* Critical to everything is **communication** and getting word out to as many people as possible - **keep the information flowing**
* **Seek connections** within and outside your usual circles
* **Work the media and use social media to connect with people**
* **Find or create something that ignites people’s passions**
* **Talk to everyone** you know
* Find the people who can tell the story
* Ride the wave of enthusiasm
* Whatever you do - **make sure its accessible**
* Find people and/or organisations who can talk to others about what you are doing (never underestimate the **power of word of mouth**)
* **Ask for help** and ask for commitment

### Resources for building interest:

1.1 Communications, communications, communications (page 22)

1.2 How to ask for support and commitment? (page 21)

1.3 Checklist for holding an event (page 23)

1.4 DSO’s in the UK (page 25)

1.5 Some examples from our work (page 29)

## 2. Maintaining interest and building capacity

Before we even started, our partner, In Control NSW was applying for funding to help us establish a Disability Support Organisation (DSO) in the Hunter. In Control made an application to the Practical Design Fund, an initiative of the Australian Government Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA). By early December we found out that we were successful. This funding helped us to do a whole lot of things (including writing this report sharing our experiences with others).

The funding enabled us to do three important things:

* We could employ people to do the work on the ground and keep things moving. We were all working towards a pretty tight deadline (The day of the Launch of the NDIS in the Hunter which was, at this stage, about 6 months away). Without this funding things would have taken much longer
* We could access resources to support us at the meetings we were starting to have (i.e. Auslan Interpreters, costs of hiring rooms for meetings, tea and biscuits for the meetings)
* Hold public events to keep the interest going

We also received a lot of in-kind support and we built a lot of relationships in the process.

Two groups were set up and met regularly.

“I have been pleased we’ve spent so much time working on the vision and those strategic goals and objectives; because as long as we have that in mind then all the little decisions along the way got to ultimately be good at this point in time” Working Group Participant

**The working group** was a group made up of 0- 20 people with disability, family members and allies.

The first meeting of the working group was held within three weeks of our big event. Even at the first meeting discussions started to focus on three key issues that we were to talk about again and again.

**Vision Values and Mission** or ‘who we are, what we want to achieve, what we believe and what we do” was one of those key issues Discussion of this key issue went on for the next few months. We got clearer at each meeting. It was very important to have this discussion and to think about the issues from all the different angles. Another one of the big learnings for us was that it was important to have enough time and space to explore this important issue.

By the time we came to write the Constitution (see last section), we were pretty clear on what we wanted to say and how we were going to say it.

“If you don't give your idea a chance to create a new possibility then you will never know if your idea could have made a difference” Working Group Participant

The other issue we talked about right from the beginning of the working group meetings was: **What would a Disability Support Organisation do?** These were difficult conversations. They are not yet complete. We hope we will continue to change and rethink these as the opportunities unfold. This was and remains a difficult area for us. Partly we had to imagine what the ‘world’ would look like once the NDIS was introduced. We also had to imagine what would be our roles in ensuring people with disability and families had more voice, more choice and greater control. This part of the conversation included, of course, more about our values, vision and mission and also about how our DSO could be financially sustainable. From these issues evolved conversations about our constitution (see last section).

Another topic that generated almost more emails and discussion than any other topic was that of **our name**. We learned that finding the name that was right for us also took some time. It really felt like we were incubating that name. In the end - Community Disability Alliance Hunter (CDAH) was not just pronouncable when used as an acronym ‘Ceda’), but was also agreed to by almost everyone.

So in hindsight, what was important was a climate where people could express their ideas safely. It was a space where we tried to let go and test long held beliefs and opinions. We tried to think outside the box. Like everyone, when we don’t know what the ‘new world’ will look like and we don’t know what will be possible. But we continue to try to ‘see’ the new possibilities with ‘new eyes’.

The final key issue helped us with the first two issues. We had **lots of conversations about developments related to the launch of the NDIS** (see also Section 4.2). We were lucky as there were many people involved and committed to the working group. We had a consistent core group of people. These people were all doing lots of work and putting in lots of time. We also had a lot of people who were not able to come to meetings but knew a lot about what was going on and contributed through email.

“I want to see this DSO succeed” Working Group Participant

The other group that was doing lots of work was the **Project Steering Group. The Project Steering Group met weekly and was** made up of staff we employed with the funding and people from In Control. Receiving the funding from FaHCSIA meant we had two people working pretty much constantly on establishing the DSO. This was fantastic. It also kept us focused by adding some extra pressure to have our objectives achieved (including producing this resource) within a very short time timeframe.

One of the things we learned about having a Project Steering Group was that it helped to have a work program, to stick to it and try not to fall behind. A lot of the operational work got done by that group. This created space for the local Working Group to talk about the big picture and spend time exploring the ideas.

“Having a plan and sticking to it really helped us stay on track” Steering Group Member

The focus of the Steering Group was really to help the two staff members organise things (such as public forums and workshops), as well as to provide opportunities to think through and discuss mostly operational matters.

One of the areas in which the Steering Group took a lead, simply because of its areas of expertise, was **thinking about how a DSO could be financially viable** and, in fact, how it could thrive. The Working Group had, over time, provided a good understanding of what we were (and were not) wanting to do. The Steering Group then used this understanding and collaborated with a company with extensive experience in financial modelling to think through what might be possible (see section 5).

One of the things we learned was that whilst it was great to have some funding almost from the beginning, it also added pressure, mostly in the form short time frames. It was added pressure we all could have done without.

### Key things we learned in maintaining interest and building capacity:

* It’s great to have a **bit of money** to help you cover the cost of making things inclusive of everyone
* **Don’t rush the big conversations** (who we are, what we believe in and what we do) - give them time and space to incubate
* **Find your collective strength/s and challenges** and stay on top of your challenges
* Have some **structures** and a **timeframe** to help guide you. (It is too easy to get distracted and go off on a tangent)
* **Allow time** for what people feel strongly about, allow for **people’s passions** to come forward

### Resources for maintaining interest and building capacity:

2.1 Sample Working Group Agenda (page 33)

2.2 Vision, Mission, Values or “Who we are, what we believe and what we do” (page 33)

2.3 Steering Group Work Program (page 35)

## 3. Building relationships and finding partners

One of the things we started working on right from the start was building relationships and looking for partners. What we had in common was that all of us, many of whom had been involved in the world of disability for a long time, had a sense that disability was a ‘hot issue’, the ‘flavour of the month’. Almost every day there were media announcements and new developments; it was all happening.

“Disability - it’s the new black” Steering Group Member

We could see that the announcement of the NDIS had an impact on people, communities and neighbourhoods. We set about finding partners who could also see the potential of the scheme and who could assist in creating more inclusive communities.

Building relationships with the right organisations was really important from the start because we wanted the DSO to be embedded in the community. We wanted it to be connected to community organisations that provide supports and connections for people in the community, irrespective of people’s abilities. We were looking for partnerships with mainstream organisations, such as neighbourhood and community centres, who share our passion for inclusion and social justice.

At this stage it might be good to talk about **who to partner with**. We had started to make some waves and some inroads. We were becoming known and, dare we say, a bit popular. We had some offers from disability service providers to support us, to form partnerships and alliances with us.

However, we decided not to partner with or be sponsored by traditional disability service providers. We felt this would put us in a compromising position and possibly, later on, potential and real conflict of interest. In our discussions about who we are as a DSO and what we wanted to do, we also became clearer about being independent from traditional disability service provision.

We found community organisations that were willing to partner with us, (see the list of organisations at the front of this document) as well as support and auspice us in our many funding submissions. We also found organisations willing to offer in-kind support and several organisations did fantastic pro-bono work for us. Yet what we did not find was anyone who was willing to back us up with real resources, meaning money, office space and equipment and free access to telecommunications. Even at this stage, we have several funding submissions on the go, mostly hosted by local agencies and we are still looking to for partners who can assist us financially.

In terms of creating local and regional relationships, we spent a considerable amount of energy on becoming known and recognised by others. We worked hard to establish relationships with mainstream (non-disability specific) organisations and also established good links with Aboriginal and ethnic community organisations. Given the diversity of people living in the Hunter, being responsive to and inclusive of that diversity will be important for our future.

“I am bitterly disappointed and angered the NDIS has been renamed DisabilityCare Australia” Working Group Participant

Most importantly we worked on two relationships. One is our relationship with the community of people with disability and families in the Hunter and the other is our relationship with the National Disability Insurance Agency, or what is now called, DisabilityCare Australia.

### Key things we learned from building relationships and finding partners:

* **Get clear about what you want**
* **Get clear about what you can offer**
* **Get clear about the types of organisations with which you want to partner**
* **Try to connect** with people with disability from all communities
* **Talk about why you are passionate** about your DSO and what it can offer to people with disability, families and the community at large

### Resources for building relationships and finding partners:

3.1 Partnerships and Sponsorship – Beware of strange bedfellows (page 38)

3.2 Thinking about what you have to offer - your assets (page 38)

4. Having a voice around the NDIS

The energy of local people with disability and their families was electric and necessary to keep all of us moving. People were interested in setting up an organisation to help make the NDIS work for people with disability and families. For our emerging DSO it was important to get word out to people with disability and their families and talk about what can be possible. So we got busy. We got busy running workshops and forums for people with disability and families to not only learn about the NDIS. Perhaps more importantly, these workshops and forums allowed us to hear from and ask questions of people with disability and families who had made choices that meant they had greater control over their lives.

We’re taking the initiative: learning together, supporting each other and doing all we can so people with disability can have good lives, enjoying the same rights and opportunities as the rest of the community” Newcastle Herald, opinion piece by Cath Mahony and Linda Hughes

As part of our funding from the Practical Design Fund, we ran three workshops in the Hunter. The workshops focused on:

* The NDIS and the NSW government’s transition to individualised funding
* Imagining how services and supports could give you the life you wan
* Thinking and planning for a good life and how to make it happen
* Practical ways to get the most of individual funding
* What supports and assistance are available in navigating the new system

In November 2012 we started to actively communicate about our ideas and the DSO to people in the community and we reached over 350 people directly through our big event, our workshops and through our newsletters. There must be thousands more who read about us in the local papers or heard about us on local radio.

One of the reasons In Control NSW is interested in getting involved in the establishment of a DSO in the Hunter is because it is to be a launch site for the NDIS. Policy decisions will be implemented and tested here first. In Control NSW, with its focus on bringing about systemic policy change to enable people with disability and their families to direct their supports and to advance and uphold the rights of people with disability, is interested in developing a strong regional voice of people with disability and families as a way to influence and shape how the NDIS will actually work.

"You guys are doing an amazing job of getting info out there to everyone. It was an excellent seminar.” Seminar Participant

We made sure we got to meet everyone who was someone in the NDIA (now DisabilityCare Australia) and the Hunter. At our meetings we spent quite a lot of time talking about what we learned and heard. Members of the Working Group participated in co-design workshops, attended public forums, organised meetings and asked people they knew about what they knew. Members of the Working Group also participated in assessment trials and sat on interview panels. In short, we tried to become as connected as we could in the time we had so we had the best chance of knowing and understanding what might happen next. Of course we also hoped that some of our ‘usefulness’ might eventually aid our search for funding.

### Key things we learned from having a voice around the NDIS:

**Talk to everyone- inspire people with your vision**

**Ask** lots of **questions**

**Get to know the people who make the decisions**

**Be useful to the people who make the decisions**

Find a way to **advise the people who make the decisions**

### Resources for having a voice around the NDIS:

4.1 Strategies for influencing policy making (page 39)

## 5. All about Money – the importance of financial viability and sustainability

The next part of the report is certainly the most important and some parts of it are still unfolding as we write this resource.

In this section we will talk about money from a range of different perspectives.

* Firstly, we want to look at the role of money in establishing a new organisation led by people with disability and families.
* Secondly we will talk a bit about how we went about thinking about the financial viability of the DSO in an NDIS as envisaged by the Productivity Commission.
* Finally we want to talk about some of the apparent changes as the NDIS unfolds in terms of roles and functions of a DSO (as described by the Productivity Commission) and some of our fears and concerns that these changes may have on the viability of any DSO.

**Establishing our organisation** was aided by receiving some funding from the Practical Design Fund which enabled us to employ two, part-time local workers. This meant that we could move fairly quickly and comply with the deadlines set by the funders. However, we think it is possible to do all the work that needs to be done on a voluntary basis. Of course, then the pace of establishment is dictated by the amount of time volunteers can make available. It is really important for us to say that all the work done by the Working Group and some of the work done by the Steering Group was time volunteered by the people involved and without that, CDAH would have never gotten off the ground.

From what we learned about starting up an organisation of people with disability and families, you will need a little bit of money to make it all accessible for all people with disability. In our case we did not use our limited funding from the Practical Design Fund to assist people with transport, but we spent some of the funds in making the meetings accessible for everyone. The single biggest cost we found in engaging with everyone who wanted to be part of establishing CDAH, was paying for Auslan (Australian Sign Language) Interpreters.

When we started to talk about the **financial viability of the DSO**, we based much of our thinking on the Productivity Commission report and also on trying to read whatever information was available at the time. Whilst much of our thinking is still evolving as we write this resource, it might be useful for us to share how we went about thinking about what we would do and how we would be viable financially.

Talking about financial viability was difficult at first. Most of us were used to thinking in terms of block funding and also thinking that we could not ‘take money from people’s packages’. Our conversations were a bit stuck in finding ways to attract block funding. However over time, and with more room to think we came up with the following, non-exhaustive list of functions that are easily compatible with what we want to achieve and therefore might want to do:

**Information Gathering** Initial phone enquiries or walk-ins to assess need

**Assessment Support** Prepare for eligibility assessment.

Support people to attend eligibility assessment

Support people to challenge outcomes of eligibility assessment

**Planning** Assist people to develop their plan (basic)

Assist people to develop their plan (complex)

**Coordination** Assist individuals in the coordination of supports and services to implement their plan.

Coordinate and follow - up supports, service delivery and payments in line with individual plans

**Human Resources** Basic advice and advocacy role (e.g. sit with the person in an interview, put questions together, role play and practice)

Assistance with recruitment and selection

Legal support

**Negotiation & advice** Provide advice to individuals on how to negotiate with potential providers and get the most out of their package

Performing negotiation on behalf of individual/s

**Capacity Building** Run workshops

Deliver generic short courses covering fundamental skills on an individual basis

Informal support/peer mentoring and development

Tailored capacity building services

Consulting to service providers on a range of issues that assist services

**Fund administration** Pay invoices and other expenses

Report regularly to individuals,

Manage acquittals and communications with funding agency.

To help us think through all this we got some help from people who know about financial modelling. With their help, we started to work through what we would need to do to make this model work. In addition, we have applied for grants through clubs, banks and corporate Australia.

Since then however, it has become clear that there are **changes to the expected role of DSOs** and that some of the functions that we (and the Productivity Commission) had envisaged as being done by a DSO have become part of the role of DisabilityCare Australia.

As we write this resource, it is hard to imagine how a DSO could be financially viable without some core funding to kick start it. If viability funding and organisational change funding were to become available to help services prepare for the NDIS, we would argue that this funding should also be available to kick start a DSO since DSOs are a new model of service. This new model, aiming to create a place where the voice of people with disability and families in making choices and taking control can be practiced, supported and explored is paramount in the new system.

### Key things we learned about money:

**If money is not within the skill set of your group, see if you can find someone with those skills**

**Thinking outside the box takes time especially** if money is not your strength

**Play with your ideas**- test them out

If you can **get some money to make the initial meetings accessible** that would be great

Try and **find some core funding**- maybe from a non-traditional source

### Resources for learning about money:

5.1 Market Research – what would people want to buy from a DSO (page 40)

5.2 Financial Modelling (page 43)

## 6. Creating the Organisation

As we write this resource we are about to become incorporated as a legal entity. We have chosen to become an Incorporated Association under the NSW Associations Incorporation Act 2009. All States and Territories appear to have different legislation so it makes little sense to talk about exactly what we did with CDAH. You might also choose to become a different legal entity such as a company registered with ASIC (Australian Securities and Investments Commission). You might choose to become a co-operative or explore any of the newer ‘hybrid’ legal structures used by some social entrepreneurs. Whatever structure you choose, make sure it fits your purpose and know what the rules are and follow them. We learned a few general things in our process that might be useful to others:

* **Get very clear about your vision, mission and values** beforehand- this will make the word - smithing for your organisations aims and objectives much easier
* **Get clear about who your members are and** what membership rights they have – we talked about the role of allies, what role organisations can play, who has full voting rights and who does not, we talked about family members and their role in a user led organisation
* **Get clear on the steps** you have to follow and follow them
* **Make sure you communicate** all critical elements of the establishment with all people who have been involved and have contributed

### Resources for creating the organisation:

6.1 Working out what structure will best for you (page 43)

6.2 Involving everyone- getting clear about the skills people bring (page 43)

## 7. What next?

At the time of writing we are about to incorporate and register with DisabilityCare Australia. Our biggest worry at this stage is that we will not have any core funding and we will not be able to do at least some of the work we want to do. We might have to think differently about how we do this. Perhaps we need to turn towards other funding sources, such as crowd funding and philanthropy and engaging with people on what we believe in and what we think we can achieve.

We are a vibrant, energetic group of people with disability, families and allies and we want to make this work, so that we start delivering on our vision: **an inclusive and just society where people with disability have voice, choice, control and active citizenship through social, economic, cultural and political participation.**

## 

# Resources:

## 1. Building Interest

### 1.1 Communication, communication, communication

* Talk to everyone you know
* Find the people who can tell a good story
* Use your media contacts
* Ride the wave of enthusiasm
* Keep the information flowing all the time to everyone
* Make sure everything is accessible
* Use as much social media as you can
* Find people and/or organisations who can talk about it to others (don’t underestimate the power of word of mouth)

### 1.2 How to ask for support and commitment?

For many of us asking for support and commitment from others is hard, especially when we think the other person is already busy, maybe even overwhelmed. Don’t assume you know what another person is willing to give and contribute.

Ric Thompson, from Inclusion Works in Queensland, wrote a paper called “The Art of Asking”. He says there are a few questions to keep in mind:

* Why are you asking?
* What are you asking for?
* Who are you asking and who does the asking?
* When do you ask?
* Where do you ask?
* How will you safeguard (what you ask for)?

(<http://www.cru.org.au/index.php?option=com_content&view=article&id=111&Itemid=107>)

If you want to look at an expert in the art of asking, watch this you tube clip called the Art of Asking by Amanda Palmer, former lead singer of the Dresden Dolls. (Note: it takes a bit of getting used to, but then it blows you away) <http://www.youtube.com/watch?v=xMj_P_6H69g>

### 1.3 Checklist for holding a public event

The following is a checklist of operational matters when holding a public event. It was put together from a range of sources and you will need to adapt it to your specific circumstances.

| Checklist for Events | | |  |
| --- | --- | --- | --- |
| Event Name |  | | |
| Date and Time |  | | |
| Location |  | | |
| 1-3 months in advance | | | |
| Task | Assigned to | Started | Finished |
| Get clear on objectives and aims |  |  |  |
| Have a budget |  |  |  |
| Identify key speakers |  |  |  |
| Confirm dates (consider time of day weekday and time of year) |  |  |  |
| Book venue (consider accessibility, proximity to accessible public transport) |  |  |  |
| Consider catering |  |  |  |
| Early announcements (long lead media, community service announcements, websites) |  |  |  |
| Use social media (send invitations to contacts, promote event on facebook pages; use a # tag to promote the event on twitter) |  |  |  |
| Create fliers and promotional materials (ensure electronic information is available in accessible formats) |  |  |  |
| Take registrations (online - make sure it is accessible, paper based, phone, etc) |  |  |  |
| Prepare your Speakers |  |  |  |
| Organise support staff (Interpreters, personal carers, etc.) |  |  |  |
| 1 week before | | | |
| Review numbers |  |  |  |
| Short lead media (have you Speaker ready to do media) |  |  |  |
| Confirm numbers with venue and ensure they understand access requirements (ie. Tables to put plates and cups; paper cups, straws, accessible pathways accessible toilet is not full of cleaning products, etc) |  |  |  |
| Confirm catering |  |  |  |
| Ensure supports are available |  |  |  |
| Pull together all the stationery you need for registration and on the day |  |  |  |
| Ensure you confirm with everyone who has registered |  |  |  |
| Make sure you have all your promotional materials |  |  |  |
| The Day before | | | |
| Send final ‘see you tomorrow’ email |  |  |  |
| Ring people who have asked for a reminder |  |  |  |
| Create name badges, attendance list, evaluation forms |  |  |  |
| Ensure all electronic presentations are on a USB/ computer |  |  |  |
| Have all materials for people with additional needs (Bbraille, plain English, a bowl for the guide dogs, etc.) |  |  |  |
| On the Day | | |  |
| Get there early |  |  |  |
| Set up registration desk |  |  |  |
| Manage Speakers |  |  |  |
| Ensure all technology is working (Audio-visual; microphones,etc) |  |  |  |
| Welcome and connect support staff to relevant people |  |  |  |
| Hand out materials, evaluation/ feedback forms |  |  |  |
| Afterwards | | | |
| Send thank you notes/ emails to everyone |  |  |  |
| Return any borrowed equipment |  |  |  |
| Do media follow up |  |  |  |
| Pay bills and check everything against budget |  |  |  |
| Meet with everyone who was involved, discuss, reflect and plan for what’s next (and remember to celebrate) |  |  |  |
|  |  |  |  |

And if you are worried about any legal issues you might have to consider, PILCH Connect has created this fantastic list which should help you with thinking those through: [http://www.pilch.org.au/eContact speakers and confirm datesventsgeneral/](http://www.pilch.org.au/eContact%20speakers%20and%20confirm%20datesventsgeneral/)

### 1.4 DSO’s in the UK

The following are the overheads from a presentation given at our NDIS event by Belinda Epstein Frisch about DSO’s in the UK





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### 1.5 Some examples from our work:

**1.5.1 Our Web Flier for NDIS In the Hunter: getting in Control**

**A one day event for people with disability, their families, friends and allies, service providers and other interested people**

**Saturday 24 November – Newcastle**

**On the 1st of July, 2013, the National Disability Insurance Scheme will be launched in the Hunter, one of five launch sites across Australia.**

* Interested to know what this means for you and your family?
* Want more information to be better prepared?
* Hoping to find ways to strengthen the voice and involvement of people with disability and their families?

**Then this event is for YOU**

### The event will include:

* First-hand experiences of people with disability and their families who lead the lives they want as the result of having control of their individual funding.
* An update of the NDIS in the Hunter by a representative of the NDIS Launch Transition Agency.
* Ideas about how to give voice, choice and control to people in the Hunter, including information about disability support and user led organisations within Australia and overseas.
* A forum for people with disability and their families to discuss what they can do NOW in the Hunter to prepare for emerging opportunities.

### Who would benefit by attending?

* People with disability, families, friends and allies interested in emerging opportunities
* Service providers interested in assisting people with disability to build the lives they want
* Anyone interested to know more about the NDIS as it begins in the Hunter

**The NDIS promises individualised funding for people who need long term care and support. If you are wondering what this could mean for you, come and hear real stories from everyday people with disability and families in NSW about the who, what, when, where, why and how of using support.**

### Speakers Include:

* People with disability and family members sharing their experiences of individualised funding and managing their own supports.
* A representative for the NDIS Transition Support Agency.
* People who know about user led organisations and the contribution they can make to improve people’s lives (in the afternoon session for people with disability, family members and friends only).

### Venue:

Panthers Newcastle  
Cnr King and Union Streets Newcastle West

### Event Time:

Registration Opens at 9am  
9.30 am -1.00 pm – All welcome  
9.30am – 4pm for people with disability, family & friends  
Let us know if you require support to attend  
Please Note: afternoon session is only for people with disability, family & friends & will focus on the development of user led/ disability support organisation in the Hunter  
Lunch will be provided for those staying for the afternoon.

### Cost:

Service providers – $100  
People with disability, family members and friends – $15

### Registration:

[Click here](http://www.formstack.com/forms/?1300676-IcEpZ7HLEQ) to register on-line  
Or email: [info@mind-the-gap.net.au](mailto:info@mind-the-gap.net.au)  
Or call: (02) 495 70 846

1.5.2 Our **Media Release**

### For Immediate Release Tuesday 22 January

### Hunter People with Disability: Doing it for themselves

### With the Hunter launch of the National Disability Insurance Scheme in July, a group of people with disability, their families, friends and allies are making history in the establishment of a new organisation run for and by the very people it aims to help.

### Tomorrow sees the second meeting of the Hunter Disability Support Organisation, made up of people with disability, their families, friends and allies.

### According to its Community Development Worker, Ms Linda Hughes, “this new group is a first for the Hunter Region, providing a collective voice for people with disability and those who are close to them. We’re working for the change we want to happen: learning together and supporting each other and doing all we can so people with disability can have good lives, enjoying the same rights and opportunities as the rest of the community.”

### The decision to establish the group in the Hunter came from a local forum for people with disability and their family and friends last November. “We highlighted the positive impact of similar groups to ours in the UK. Less than two months later, we’re off to a great start. We have about 20 people who have expressed interest in being part of our working group and another 45 interested members.”

### “It’s not easy to bring a new organisation to birth – especially one that wants to do things differently and bring about social and cultural change. It’s about changing our thinking as well as our actions,” Ms Hughes said.

### “Right now we’re busy getting the fundamentals in place: what we want to achieve for ourselves and the broader community, our projects and tasks in the short and long term and the values which will govern all that we do. What’s exciting about this process is the wisdom, expertise, willingness and energy of the working group. We’re doing it by ourselves for ourselves,” says Community Development Worker Catherine Mahony

### “The time is right with the roll out of the NDIS around the corner and other changes happening in disability service provision. In fact the 2011 Productivity Commission Report which recommended the NDIS recommends and highlights the importance of disability support organisations like ours which are independent of government and disability service providers.”

### “We’ve got a lot to do in a short time frame and we’re really keen to find some community partners who share our dreams and values for people with disability and would like to work with us in this new endeavour,” Ms Mahony said.

### The development of the Hunter Disability Support Organisation is funded by the federal government’s Practical Design Fund (PDF), for innovative projects which will support and enhance the implementation of the NDIS. It is auspiced by InControl Australia.

### Media Opportunity

### All media are invited to meet the members of the Hunter Disability Support Organisation Working Group tomorrow, Wednesday 23 January, from 12.30-1.00 pm at “The Place”, corner of Frederick and Pearson Streets Charlestown, at the southern end of Charlestown Square. [Click here](http://www.theplacecharlestown.org.au/index.jsp?topic=148) for more details.

## 2. Maintaining interest and building capacity

### 2.1 Sample working group agenda

Most times our agenda looked similar; the agenda for a meeting in mid March is typical;

**DSO Meeting 18 March 2013**

* Attendance
* Apologies
* General Update:
* Sub- Committee Update:
* Upcoming Workshops
* Market Research for the DSO
* DSO Functions
* Mission, Vision Values
* DSO Name
* Next meeting

### 2.2 Vision, Mission, Values or “Who we are, what we do and what we believe

Creating the vision, mission and values of any emerging organisation is critical. The **vision** describes how the future is imagined (for example, a world without discrimination). The **mission** describes what we do – how we will achieve the vision (for example, we work to eliminate barriers) – and our **values** describe what we believe in to achieve the vision (for example, working in partnership with people with disability).

A vision should take hold of your imagination and energise you. A vision ought to describe something that ignites your passions and makes you want to get involved. A vision should describe a future that is different from the past.

An effective vision should have six key characteristics. It should be:

* **Imaginable**: It conveys a clear picture of what the future will look like.
* **Desirable**: it appeals to the long-term interest of those who have a stake in the enterprise.
* **Feasible**: it contains realistic and attainable goals.
* **Focused**: It is clear enough to provide guidance in decision making.
* **Flexible**: It allows individual initiative and alternative responses in light of changing conditions.
* **Communicable**: It is easy to communicate and can be explained quickly.

(Kotter, 1996:72; Leading Change, Boston Harvard Business School)

2.2.1 At CDAH we are working with this:

**Who we are:**   
  
Community Disability Alliance Hunter (CDAH) is a user led organisation, run by and for people with disability and their families with the aim of assisting people to get the support they need to live the lives they choose. We are an independent, collective voice committed to full inclusion and active citizenship.

**We believe that each person with disability has the right to:**

* live a good life as a valued and active citizen
* have a voice, make choices and be in control of their lives
* be recognised for their skills, gifts, abilities and potential
* have/experience genuine and meaningful inclusion in the social, economic, cultural and political life of the community
* have a collective voice which promotes our common experiences

**What we want to achieve:**   
  
The Community Disability Alliance Hunter (CDAH) strives for an inclusive and just society where people with disability have voice, choice, control and active citizenship through social, economic, cultural and political participation.   
  
**What we do:**

* Increase the knowledge, skills and capacity of people with disability and their families to lead lives typical of most people through information, advice, mentoring, peer support, training and development
* Assist people to get the most out of their packages of support
* Build the capacity of the community to welcome all people
* Share our collective lived experience to empower people with disability to have voice, choice and control
* Uphold and be guided by the principles and articles of the United Nations Convention on the Rights of Persons with Disabilities

### 2.3 Steering Group work program

Receiving funding almost always means having to fulfil some external objectives within a particular timeframe. We had four key objectives and our timeframe was very tight (about 7 months with the summer holiday period in between). We developed a work program that we pretty much stuck to and we have included it here because if you want to set up a DSO this might be useful. We used this work program as the framework for our meeting and at any given time in the project we pretty much knew where we were up to in our work.

**Steering Group Work Program**

**Goal: To establish a DSO**

Objectives:

1. To build enthusiasm for change and build capacity of people with disability and families in the Hunter
2. To influence NDIA in roll out of NDIS in the Hunter
3. To develop relationships with allies who support the empowerment of people with disability and families
4. To support working group to lay foundations for DSO

**Objective 1**

| Objective | Strategies | What and other considerations | Time frame |
| --- | --- | --- | --- |
| To build enthusiasm for change and build capacity of people with disability and families in the Hunter | Hold workshops | Providing people with vision and skills while simultaneously build enthusiasm for DSO  3 half day stand alone workshops, more intimate  Attempt to reach range of people with disability and families by having each workshop in different areas, at different times, on different days with content that is consistent with the typical roles a DSO may play  Workshops in first half of project  Decide aim of each workshop, content, process |  |
| Develop resources to communicate about DSO | Initial resources – general fact sheets – what is a DSO, How might a DSO help you especially plain English  Resources that provide information about possible roles |  |
| Develop communication strategies | Build on connections, ie communication strategies from 24th November  Opinion piece in Newcastle Herald  Possible comment on local issues  Website – immediate What is a DSO |  |
| Social media – facebook page  Twitter handle @NDISHunter  NDISHunter website |  |
| Local traditional media – strengthening and using existing |  |

**Objective 2**

|  |  |  |  |
| --- | --- | --- | --- |
| Objective | Strategies | Other considerations | Time frame |
| To influence the NDIA around the roll out of NDIS in the Hunter | Participate in NDIA forums |  |  |
| Develop relationships with local NDIA staff |  |  |
| Brief targeted submission from DSA Steering committee |  |  |

**Objective 3**

|  |  |  |  |
| --- | --- | --- | --- |
| Objective | Strategies | Other considerations | Time frame |
| To develop relationships with allies who support the empowerment of people with disability | Scan Hunter community for potentially like-minded allies | Seek out the following agencies:  XXX |  |
| Talk at neighbourhood centres conference | Talk to XXX |  |

**Objective 4**

| Objective | Strategies | Other considerations | Time frame |
| --- | --- | --- | --- |
| To support working group to lay foundations for DSO | Attract membership of working group  Keep the group as a healthy functioning group | Email to locate best time and day for working group meeting – by 23.1.13 can plan future meetings |  |
| Support participation needs of working group | Ongoing |  |
| Develop a data base of interested individuals | Name, address, phone (including mobile) email person/ parent / service provider  List serve |  |
| Assist working group to determine vision, mission, roles of DSO | Structured discussion at working group  ? planning frameworks  roles – provoke discussion eg on role as financial intermediary or assemble a package |  |
| Assist working group determine infrastructure required |  |  |
| Assist working group to develop a constitution |  |  |
| Assist working group to incorporate the DSO |  |  |

## 3. Building relationships and finding partners:

### 3.1 Partnerships and Sponsorship – Beware of strange bedfellows

It is easy to get distracted and sidelined by issues. To stay focused on the path is critical. Partnerships and sponsorships can really boost your efforts, but they can also severely derail you and get you stuck in a whole lot of debate and arguments, both internally and with the potential partner/ sponsor. Below are four key questions you might want to ask to work out early on whether the offer is worth pursuing.

* Does it fit with what we want to achieve?
* Will we stay in control?
* Will we be asked to endorse, or seen by the public as endorsing, the partner/sponsor?
* Are there any conflicts of interest?

If you find yourself a partner/ sponsor you want to work with, have a look at this ‘Ethical Sponsorship Policy Template” which appears to cover some of the key issues you may need to address to clarify your position (<http://www.corporatecritic.org/info/espffold/ethics4.aspx>)

### 3.2 Thinking about what you have to offer - your assets

The little graphic below helped us to think about what we had to offer. It might jolt your thinking as well. Most likely you are very rich in knowledge (don’t forget to include not just your lived experiences but also all your connections into community) and human resources (think about the volunteer hours spent and all the expertise of those volunteers), while you are probably rather poor in physical assets and actual money resources.

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## 4. Being in the ‘know’ – having a voice around the NDIS

### 4.1 Strategies for influencing policy making

“All too often, the story of the little boy {Sorry for the sexist nature of this quote} and the hammer remains apposite to policy design. The little boy, having been given a toy hammer as a gift, would use the tool for every task he confronted, regardless of its suitability.”

(N. Gunningham & P. Grabosky (eds.), Smart Regulation: Designing Environmental Policy, Oxford University Press, Oxford, 1998, p. 89

Choosing the right tool for the situation seems to be one of the mysteries of how we can influence and shape policy making. No doubt there is a fair bit of serendipity – just purely being in the right place at the right time – but there are also some strategies and tools people have used over many the year to influence policy making. Below is a non–exhaustive list of some of the strategies we used:

* Be persistent – have ‘stickability’
* Develop connections with people who know the people you want to meet (network)
* Be helpful and useful when you can
* Don’t be afraid to provide frank feedback or ‘constructive’ criticism; if you can think of a solution suggest it
* Send the right people to do the right job
* Talk about your vision, what you want to achieve, and how you see that happening. If you find yourself being bored with what you have to say, chances are the listeners are bored as well. Let your passion influence your talking.

## 5. All about Money: the importance of financial viability and sustainability

### 5.1 Market research - what would people want to buy from a DSO

One of the things we struggled with is understanding what people with disability and families might buy from a DSO. Because we are all thinking about things that have not yet happened and we don’t know what that will look like, we did two things that helped us understand what people might be interested in and consequently helped us think about what we would offer.

**5.1.1 NDIS-opoly**

Sometimes playing a game takes us out of our usual ways of thinking and gives us some freedom to think outside the box more easily. So here’s a simple idea:

* get some monopoly money and put different amounts in as many envelopes as there are people
* set up your DSO shop ( make labels for the things you have on offer)
* give people their envelope and tell them this is the money they have left over after paying for the necessary disability supports (note different people will have different amounts in their envelopes)
* looking at what’s available in the DSO shop, encourage people to think what else they might like to buy that’s not there, and start to negotiate what new things could be available.

Make sure you take note of everything people suggest; this will become part of the basis for your thinking about your viability.

**5.1.2. Survey Monkey**

Below is a draft survey monkey questionnaire we did not use because we ran out of time, but you might find it useful:

Introduction:

The Hunter Disability Support Organisation (DSO) is a new organisation in the Hunter established to assist people with disability and their families get the most out of the NDIS.

We are user led: run by and for people with disability and their families. We are a collective voice of people with disability, independent of government and service provision and committed to ensuring people with disability have choice and control over their supports and their lives and are included in the community as full and active citizens.

In order to assist people with disability and families we need to know what type of assistance you want and need.

In this survey we ask you to **imagine** that you (or your family member) already have your individual support package. You have enough funding to have your basic needs met and have additional funding to build your capacity and skills to be in control of your supports. You might also wish to delegate some tasks (things you would rather not do yourself) to an organisation.

This survey asks what services the Hunter DSO could offer that you might be interested in and be prepared to pay for from your individual support package.

* 1. Support you to prepare for or challenge the outcomes of your assessment for the NDIS? This might mean the Hunter DSO provides information and advice to an individual who is dissatisfied with the outcome of the assessment.

Y/N

Comment:

* 1. Assistance to develop your individual support plan?  
     This might mean the Hunter DSO assists individuals to think about their goals and aspiration and the support they require given their individual circumstance before they go to the NDIS

Y/ N

Comment:

* 1. Co-ordination of individual supports and services?  
     This might mean the Hunter DOS co-ordinates and manages a package of supports for an individual?

Y/N

Comment:

* 1. Assist you to build your skills and capacity to co-ordinate their own of supports and services?  
     This might mean education and training to an individual to enable them to increasingly be in charge of their own supports

Y/N

Comment:

* 1. Fund administration and management?  
      This might mean the Hunter DSO would do some of the financial work on your behalf such as paying invoices, managing and reporting to you and to the funding agency

Y/N

Comment:

* 1. Assistance with managing human resources (HR)??  
     This might mean the Hunter DSO advices and provides you with assistance to recruit, select and manage staff, advice on OH&S and legal matters

Y/N

Comment:

* 1. Advice you to get the most out of your funding?

This might mean the Hunter DSO providing information on various service providers, what they offer and reviews of their service.

Y/N

Comment:

* 1. Assist you to get the most out of your funding?  
     This might mean the Hunter DSO negotiating on an individual’s behalf with service providers to get the best value for money

Y/N

Comment:

* 1. Do you want to be part of a DSO Bartering service?  
     This might mean a membership based trading service (not based on dollars but on services) connecting people with each other to deliver services needed by other members.

Y/N

Comment:

Thank you!

### 5.2 Financial modelling

At the time of writing this report we have developed, together with Matrix on Board, who donated some of their time and skills to us, a unit costing tool to assist us in making the necessary business model decisions.

The tool is too large to include here, but can be downloaded from www.cdah.org.au or email us on info@cdah.org.au

We are also working with another organisation helping us to think about the different possible scenarios and doing business planning for those. At this stage we do not have any material to share but will do so once we have something on the same website.

## 6. Creating the Organisation

### 6.1 Working out what structure will work for you

While there are company laws that apply to everyone in Australia, the Association and co-operative laws are all different in the different States and Territories.

If you don’t know what company structure is best for your DSO, it is best to type the following into your internet search engine: ‘how to choose your organisation’s legal structure Australia’.

You will get lots of links and you can look for the one or two sites relevant to you.

### 6.2 Involving everyone- getting clear about the skills people bring

It is critical to find out what the skills and knowledge in the room are and also to identify on what areas you are weak in.

The following checklist might be a good start. Naturally there are things missing and you want to modify this for your particular needs, for example, we used it but looked at if the diversity of people with disability is represented in the group.

(taken from: <http://www.adhc.nsw.gov.au/sp/training_and_development/good_governance> )







