

Communication

It's not a spectator sport

A resource co-designed with parents with intellectual disability in Tasmania



Contents

Introduction	1
Overview	4
Preparing for a meeting	5
A checklist for Writing Easy Read documents	14
3 step checklist for Planning a meeting	16
Sample Easy Read Agenda	18
The role of independent advocacy	19
My Communication Action Plan	20



Introduction

We are community educators with the **Mainstream and Me** project.

Our job is to

- **run workshops for mainstream services** so they can have the information and skills they need to work better with parents with intellectual disability
- **develop resources for mainstream services** from our point of view
- **help mainstream services to understand** what it is like for us when we use their service
- **design resources together as partners**

We hope this project will make services better, we hope it will lead people and services to **Support before Report**.



Good practice in working with parents with intellectual disability should be underpinned by an approach that addresses needs relating to both disability and the disabling barriers of unequal access and negative attitudes.

This approach recognises that:

- If the issues are seen as wholly related to the disability and personal limitations, it is difficult to see how to bring about positive change for parents with intellectual disability and their children.
- If we focus instead on things that can be changed, (eg inadequate housing) and support needs (specialised training eg educational materials designed specifically for parents with intellectual disability) this brings about more possibilities for positive change.

“When problems are seen as rooted in people's personal deficits and limitations they may seem intractable and out of reach. Shifting the focus onto features of people's lives that can and should be changed challenges the negative stereotypes that inform such thinking and opens up possibilities for social action in support of families”

Booth and Booth, 1998

There are **five key features of good practice** in working with parents with intellectual disability:

1. Accessible information and communication
2. Support that is designed to meet the needs of parents and their children based on assessments of their needs and strengths
3. Long term support where necessary
4. Clear and co-ordinated referral and assessment processes
5. Access to independent advocacy

Good practice guidance on working with parents with a learning disability,
Dept for Education and skills, 2007

This resource focuses on accessible information and communication.

Access to information is a human right. Being able to access and understand written information enables people to make choices and be active participants in our society.

Definition of Intellectual Disability

Significant limitations in

- Intellectual functioning
- Adaptive behaviour (conceptual, social & practical adaptive skills).
- Originates before age 18

The American Association of Intellectual and Developmental Disability. (2010). *Intellectual Disability: Definition, Classification, and Systems of Supports* (11th Edition) <http://aaid.org/intellectual-disability/definition>

Self-definitions

Self-definitions from parents with lived experience gives us insight into how their disability impacts on their lives from their perspectives.

“ I can learn stuff, I just learn differently and it takes me longer

“ I have problems mostly because people don't explain things properly, in this way I think it's them who makes my disability worse

“ Well my disability impacts me on different levels, I'm no good with maths or understanding government papers

“ It's easier when people show you how to do things than tell you. Sometimes it takes a few goes before I get things, but mostly I get it in the end

“ I have learning difficulties and trouble filling out forms, but I'm still a capable and caring parent

Overview

People with intellectual disability are all as different as with any other member of the community. There are however some things we can do to improve our communication with them and give them a better opportunity to participate more equitably.

In this resource, **we provide strategies** to help ensure your information is presented in a way that parents can understand and that they are given the opportunity to express their views.



Preparing for a meeting



Parents need time to prepare for meetings. They need to know the purpose of the meeting, who will be attending, that they can bring a support person or advocate and they need an agenda. ([see Easy Read Agenda page 18](#))

- **Give parents plenty of notice about the meeting.** If they have an advocate they may not be available at short notice. Parents may have support they need to rearrange and it takes time for them to properly prepare.
- **If you require information from parents, provide them with a list of questions 1 week prior to the meeting.** This will enable them to be well prepared and increase their participation in the meeting.
- **Inform parents who else will be attending the meeting and why.** Too many people can be distracting and parents can become confused when too many points of view are expressed.
- **An Easy Read Agenda will ensure the parent can follow the flow of the meeting.** It provides structure. The agenda can be used as a tool to separate ideas or issues. Parents can become very confused when a meeting is moving from one topic to another without obvious closure of ideas or issues.

“ Sometimes I can't think fast enough when they ask me things. I feel like everyone's staring at me waiting for me to answer, so after a while I just say I don't know.

“ Oh boy when there's so many of them and they're all saying this and that and then they ask me what I think ... what do I think! You've lost me, I don't know what I think now.

Please turn over....

Location, location, location

The size and set up of the room is very important. Many parents are not comfortable in a tiny room filled with many people.

The room must be quiet with no distractions from either noise or windows that look into busy spaces. Parents need to be able to concentrate without distraction.

“ Every time I go to meetings with we have to go into this tiny room and usually there's about 7 or 8 people, I feel like I can't breathe after a while. They keep checking their phones during the meeting, I think that's rude, if I did that they'd say I didn't care. One person always brings in take away coffee, that just makes me think, I'd like to have one of those.



Timing is everything

Try to stay on time and don't make meetings too long. Take advice from the person as to what best suits them. If the meeting is going to be long, the person may rather have it broken into two meetings. If this is not possible schedule in a break.

Try to schedule the appointment or meeting at a time when the parent is best able to concentrate. Some parents prefer earlier in the day. If a parent is in contact with Child Safety Services it is best to avoid the day of a contact visit.

“ Sometimes the meetings go on and on, you didn't even know you were going to be talking about some of this stuff, then you just keep thinking what's next, then I start worrying what they're going to ask me.

During the meeting



These strategies will ensure that parents can concentrate, participate actively and understand information.

- **Limit noise and distractions.** Don't just turn mobile phones to silent, put them away so you are not tempted to look at them.
 - **Only allow one person to talk at a time** – no side conversations.
 - **Try to be, and stay, on time.**
-

“ When they're late it makes me anxious. I get really nervous then.

Look at me, talk to me, listen to me, hear me

Always talk directly to the parent, not to the family member or support person.

A support person or advocate can advise you if they think the parent does not understand what is being said.

The parent may have discussed earlier with the support person or advocate that they want them to answer some things on their behalf. But you should always talk directly to the parent unless they otherwise indicate.

“*Doctors are the worse, they see you sitting there with your child, you might have a support person there just to help in case you need them, but the doctor will just talk to the support person.... I'm the mother, I know my child, talk to me.*

Before moving on from one topic, check that the parent has understood the key points that have been discussed.

- **Avoid asking yes / no questions.**
Ask the client to explain in their own words what has been discussed.
- **It can be helpful to then write these as dot points on a whiteboard.**
- **When information has not been understood, explain it again,** perhaps in a different way, consider using pictures, then check again for understanding.
- **If the person still has difficulty, ask if they would like their support person to help.**

Only then are you ready to move onto the next topic.

REMEMBER! The onus is on you to explain in a way the person understands.

Acquiescence

Watch out for signs that the parent is telling you what you want to hear, or what they think you want to hear.

Parents with intellectual disability may have developed a range of strategies to hide the fact that they don't understand information, or that they can't think through things quickly when put on the spot.

Many people with intellectual disability say 'yes' to questions or accept and agree with things, regardless of what has been asked, and often without really wanting to.

This is called **acquiescence**.

People with intellectual disability often attempt to mask their communication difficulties to avoid the stigma of being labelled as having a disability. It is very common for people to adopt a passive communication style, allowing the more powerful person to control the conversation.

Some of the possible reasons why people acquiesce:

- they are afraid to say no or disagree for fear of getting into trouble
- they find it difficult to say no or disagree with someone perceived to be in a position of authority
- the person may not understand what is said, so they cover this up by agreeing
- they don't understand abstract information so agree or are non-committal
- the person may use statements they have rote learned that 'please' others when responding to questions or conversations
- feeling frustrated can reduce the person's self-confidence leading them to agree with other people's suggestions.

Observe parents body language and what they are saying – inconsistencies might indicate that they are telling you what you want to hear rather than the reality.

Try to empower the person to talk about how you can best communicate with them – referring to them as 'the experts in their communication needs'.

Purposeful questions

Purposeful questions help to build understanding between the questioner and the parent. They give depth to a conversation and help develop relationships.

Use open questions – however even open questions can be leading.

Example: *What's better now you've got support?*

This is a leading question because it leads the person to only give the positive aspects of support.

Questions need to be neutral – otherwise they are not really a true question, but more a judgement, or statement disguised as a question. Neutral questions should come from a genuine desire to understand better.

- A good neutral question helps the client think more deeply about the question and leads to a far deeper response and strengthens relationships.
- Asking neutral questions is a very valuable skill but takes practice.

Example: *There's good and not so good things about having support – what do you think they are?*

Work slowly and with repetition – and check regularly for understanding.

understand
we are all human

do mainstream services need to do
mainstream services need to do while
meeting?

understand
we all human

listen to what we
are saying

• nice to write down
question or
in the meeting points
• make sure all mobile
are turned off and
silent.

• whispering is very
rude in a meeting
cause we are educators
think that your talking
about us.

Good Eye
look at us

When we are
talking
GIVE US FEEDBACK
when finished

• explain to us
what we were talking
and do they understand
what it means?

• In the meeting before we
start maybe ask the audience
suggestion what they
to talk about

Talk & slowly
not fast
Don't use big words
because we might not understand

Don't talk to me like I'm child & be respectful

“ I sometimes say I understand when I don't. They use jargon words and big words and then you ask them to explain and then you still can't get it cause they just talk too much and don't say the right words.

“ Sometimes you like, just don't want to say you don't understand because they'll all think you're dumb.

“ You know if you say you don't understand, well that's a bad thing to them.

“ The midwives right, they just kept telling me stuff but they were in a hurry and said I'll come back and tell you later, then they never do, then you don't get it, next thing you know they're saying you won't be able to take your baby home cause you can't learn stuff.

“ I have an intellectual disability. It means I learn in different ways but I am still a person. I am no different to other parents but I find it hard when you use language that I don't understand. Often you use lots of words when you could of said it in a few.

“ I feel like I can't ask questions because I will be judged as a person and as a parent.

Give feedback about the meeting.

Make sure the parent understands what's next or what is required of them.

- write this down or make it available in another accessible format – you might consider recording a note on the person's mobile phone, or assisting them to do so.

After the meeting



These strategies will ensure you can follow up and do what is required:

- provide feedback after the meeting
- avoid carrying on the meeting in the hallway where all participants may not be present
- support decisions made, especially when you leave the meeting
- make sure we know what is expected and required
- follow through with what you said you will do
- inform us who we can call / talk with if we have questions or concerns
- provide Easy English minutes
- allow plenty of time before the next meeting

Remember! The success of the meeting is the team's responsibility





A checklist for Writing Easy Read documents

Under the **United Convention on the Rights of Persons with Disabilities** to which Australia is a signatory, people with disability have the right to seek, receive and impart information and ideas on an equal basis with others and through all forms of communication of their choice.

Things to think about before you start

- **WHO** the information is for
- **WHAT** they need to know
- **WHY** do they need to know



WORDS

- Short, simple title
- Short, simple words
- Only one idea per sentence
- Have used concrete ideas
- Used present tense
- No jargon. Concepts are explained
- If appropriate, the reader is addressed as 'you'.
- Have used I, we, you



NUMBERS

- Small numbers written as figures – 7, **not** seven
- For very big numbers used the words “many, lots, a large number”
- Used a clock to illustrate time



IMAGES

- Images support the meaning of the words
- They are easy to understand
- Are on the left of the text
- Are as big as possible
- Images have meaning for the reader –
for example pictures that are local.



LAYOUT

- Have used large font size (at least 14 point)
- Plenty of white space. This is thinking space
- Used Arial, Tahoma, Verdana or similar fonts. No serifs
- A wide margin on the left hand side
- Graphic design does not interfere with text
- The document is structured into simple, easy to understand sections
- Sections have clear, simple titles that reflect the content



3 STEP checklist for **Planning a meeting**



This **3 STEP checklist** has been created as a tool for you to use when **planning and facilitating** meetings with parents who have an intellectual disability.

Parents with an intellectual disability can sometimes find meetings challenging.

This list has been created to help you in your work with parents:

1



BEFORE A MEETING



- Inform me about what the meeting is for
- Let me know I can have a support person or advocate
- Inform me who else will be attending the meeting
- Prepare Easy English agenda
- Provide list of questions in Easy English prior
- Distribute relevant information 1 week prior

.....

▶ ***These steps ensure that I can prepare for the meeting and actively contribute during the meeting.***

2



DURING A MEETING



- Limit noise and distractions
- Turn phones off
- Large meeting room
- Look at me
- Talk to me
- Listen to me
- Be on time

more over page...

DURING A MEETING... *continued*

- Ask relevant questions
 - Don't treat me like a child
 - Value my contributions
 - Talk about one topic at a time
 - Ensure I am ready to move onto the next topic
 - Don't take calls and talk amongst selves quietly
 - Explain why you are taking notes
 - Give feedback
 - Keep me informed about what is next
-

▶ ***These steps ensure that I can concentrate, participate actively and understand information.***

3



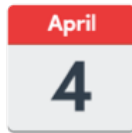
AFTER A MEETING



- Provide feedback after the meeting
 - Explain what you can do to support and understand parents with intellectual disability
 - Ensure we know what is expected and required
 - Inform us who we can call / talk with if we have questions or concerns
 - Provide Easy English minutes
 - Allow plenty of time before the next meeting
-

▶ ***These steps ensure that I can follow up and do what is required.***

Sample: Easy Read Agenda



When: Friday 5th April



Time: 11.00



Where: Burnie Linc, Alexander Street Burnie



1. Who is here and who is not
(*Present and Apologies*)



2. What we talked about at the last meeting
(*Minutes*)



3. Reports on how things have been going



4. Planning – what we need to do next



5. What did you think of the meeting?
(*Evaluation*)

The role of independent advocacy

Rights and self-determination

Despite Australia's ratification of the United Nations Convention on the Rights of Persons with Disability, people with intellectual disability still face many challenges in realising some of their most basic human rights.

For people with intellectual disability, the ability to self determine is often impeded by others' inability to communicate effectively with them. In areas such as the legal system and child protection services, advocacy plays a vital role and has benefits for all parties.

An advocate can assist with:

- engaging legal representation
- communication
- interpreting information
- upholding rights
- understanding responsibilities
- support through legal proceedings

An advocate is partisan, they work at the direction of the client.

Parents with intellectual disability who have contact with the child protection system may have feelings of hostility, lack of control and be reluctant to engage. Advocacy, particularly advocacy with a focus on self advocacy can help parents understand professionals' concerns, at the same time ensuring they know their rights and feel confident to speak up.



Support before Report
Parents with intellectual disability



**The Mainstream
And Me**



**SPEAKOUT
ADVOCACY**



Inclusion Australia

Communication

It's not a spectator sport

A resource co-designed with parents with intellectual disability in Tasmania



FOR FURTHER INFORMATION:

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