

# Personal Communication Passports

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Passports are a positive way of supporting people with sensory and communication disabilities who cannot speak for themselves by collecting together important information about them and making this accessible to others with whom they may interact. The name *Passports* was coined by the CALL Centre, who first started developing Passports and 'spreading the word' about them in 1992. Sense Scotland has pioneered the use of Passports with children and adults who come for respite and holiday placements. At the recent Sense conference workshop participants reviewed the principles of Passports, heard an account of how they were developed and used with deafblind (and other) clients, and looked at examples of real people's Passports. Main features and functions of Passports include:

## **Passports are a special way of sorting information**

Passports do not attempt to incorporate all of the available information about the person. Making a Passport means taking an overview of information from the people in day to day contact with the client. Then making choices about what others 'need to know'. For example, a Passport might have a page right up front that is headed: *If you only have a little time to learn about me, these are the three most important things*] This section may contain life and death details about techniques of eating and drinking, things that trigger outbursts of difficult behaviour (and ways of avoiding these!) and so on.

## **Passports are an efficient way of presenting information and making it accessible to a wide variety of readers**

Information in Passports is presented in a way that is simple, clear, direct and accessible, succinct, accurate and honest. To be useful, it will be highly specific and detailed and avoid vague generalizations. The way in which information is presented will not assume in the reader any prior knowledge. There will often be a page about someone's vision, not in ophthalmologist's medical jargon but in basic functional terms. For example, it will say things like:

*If you come at me from my left side, I will not see you until you are right in front of me. I might get a fright if you suddenly appear there. My sight on my right is much better Please remember to come from the right and to move objects in towards me from the right.*

or

*Most of all, I need lots of time to look at things. I get cross if people talk to me and rush me when I'm trying to look at something.*

## **Passports are a way of supporting the person, their carers and professional helpers through potentially traumatic life changes and transitions,, and of ensuring consistency in how different people understand and approach the person.**

Children or adults with disabilities, especially with communication problems, are always vulnerable, and particularly so at times of transition when they are moving from a situation where everyone knows them, to a situation where they will be meeting lots of new people and encountering lots of new situations. For example, hospital admission, respite care, holiday play schemes, moving from pre-school to nursery or school; from primary to secondary school, (or even from one class to another); school leaving. Or adults moving out of long stay institutions into homes in the community. Passports can provide some 'shared history' about someone's life and personality and ways of doing things. A Passport may contain a page headed *This is how I work best* including hints like *Tell me what you are going to do before you do it. I'm telling you this for your own good because if get pushed and pulled or don't get time to think, I sometimes get we cross]*

Even where people have an augmentative communication system, they are not necessarily always fully independent in its use. Passports need to transmit information about how exactly communication system(s) are used. (It is not enough for new staff simply to read "Fred uses objects of reference" or "Mary uses an

ORAC for communication" - many practical details are needed about how precisely the user manages the system.)

### **Passports are a way of orientating new staff quickly**

It can take at least a year to really get to know a person with severe sensory and communication difficulties but schools hospitals and units for people with disabilities have a high staff turnover and lots of inexperienced trainees, temporary staff, and volunteers. Induction of new staff is an almost continuous process. Losing carers and being looked after by new people all the time is unsettling for the children or adults. Using Passports is a way of building up the confidence of new staff, hastening the development of positive relationships; and of ensuring consistent management by rapidly changing new staff. A nurse in hospital said:

*Well I was going mad - I thought she just wasn't hungry, or that she was being naughty because she didn't like me. She spat all her food out. I didn't realize she needed a special spoon and couldn't close her lips by herself. Then I felt terrible when I read the book, I thought we'd been starving her, but at least I knew what to do. And I made sure the others read it when they came on-shift.*

Again on eating and drinking issues, a parent said:

*I can't stay there (in hospital) with her 24 hours a day because of the wee one. But at least I don't feel quite so awful about leaving her there now, because I know the nurses can read how to feed her properly, and what she likes to do.*

Sometimes information is totally practical (and so make all the difference between it being safe for a volunteer to be left alone to do something with a client, or not). For example:

- *I love going on my bike. This is how you help me*
- *Check the mark where the level of the back support is fixed (tape shows you)*
- *Now take off the back support 2 adults need to lift me One holds me safe The other pushes the back support to the bottom of the tape*
- *Tighten screw*
- *Fix straps on pedals (takes both people)*

and so on.

### **Passports should be visually attractive and readable documents**

Clients must feel positive about their own Passports, so that they feel keen to show it to others. People must find the Passport attractive and want to read it. As everyone is short of time, Passports must be easily and quickly read by readers of various ages and educational backgrounds, avoiding professional or technical jargon. Like 'sound bites', the information on each Passport page will be brief but striking, so that once read, the main points are remembered.

Passports should catch the attention by being visually interesting, whether they are desk-top published on computer or produced by hand, through the use of colour, graphics, borders, photographs, pictures and scanned images.

### **Passports are highly personalised and show the person they represent as human, unique and recognisable**

Unlike medical notes, written in a depersonalised (and often depersonalising) way, which may be quite alienating to families, Passports are meant to be highly personal. Indeed, the 'acid test' of a Passport is if a person reading it, who knows many of the group of classmates or residents, can quickly recognise the unique individual from the Passport and say confidently, by reading almost any page, "Oh yes, this is Julia. isn't it?" (If a reader can't recognise a person they know from their Passport. or can't distinguish one Passport holder from another, then there's something wrong.) When, in the Sense Scotland research, parents who had not come across Passports before were shown firstly traditional case notes with information relating to their own child, and secondly information in Passport format about an 'anonymous' child, they all said they preferred the Passport style.

One important technique for personalisation is writing the Passport in the '1st person', as if it was the client him or herself writing/speaking directly to the reader. For example:

*Please don't hold my hand or stroke it. You'll make me embarrassed in front of my friends. Just treat me like everyone else. Thank you.*

The Sense Scotland survey showed that parents preferred Passports to be written in the first person "*I hate jelly so much I might even spit it back at you, so watch out!*" Interestingly, some staff were less convinced, and preferred things like "*Fred has trouble eating soft mushy food and tends to dislike it for this reason*".

### **Passports are a way of presenting information in a way that is positive and empowering both to the person they represent and to the reader**

Passports are not a catalogue of the owner's disabilities and difficulties, they are positive problem solving documents. They represent an acceptance of the Passport holder as they are, and focus on working solutions rather than on problems. They are potentially empowering because they offer practical ideas on ways forward for both the owner and the reader.

Passports are like 'manuals'. If you buy a new household appliance, the manual does not tell you about all the things the equipment does *not* do. It tells you lots of things it *does* do. and what you can do to 'get the best' out of this functionality. It will also have a 'troubleshooting' section warning of the kind of things that may go wrong. It gives practical advice on how you can prevent these happening, or, if necessary, how you can identify the nature of any problems that arise, and what steps need to be taken to resolve such problems.

Passports are also a kind of 'advance PR'. If you were about to join a class or a small group home as a new member, what kind of advance information would you wish the people already there to have about you? A list of all your problems? Or a positive sounding set of strategies and techniques for preventing or repairing breakdowns in communication? For example, a Passport Page might be about:

*Things I am Good at (or My Strengths)*

*Things I can do for Myself*

though there might also need to be pages like

*Thing I need someone to do for me*

*Thing I need a bit of help with*

### **Making Passports is a way of valuing the role of family and carers, and of giving them more control**

A Passport can save endless repetition by parents /carers; may cut down distressing or frustrating incidents; ensure consistent management, and smooth the integration of new staff working with a client. They stress the fact that people in day to contact with the client know more about them than so called 'experts' who may review the person once every year or so.

Passports emphasise how all of the people around the client are important and that the client's function can be enhanced by the way they act and interact - after all, they have more potential for learning new techniques and changing their behaviour than a person who may have disabilities and learning difficulties.

Passports will usually include a page or pages headed *Important People in My Life* (often with pictures and a little background). It can be amazing to count it up just how many people are important on a day to day basis, and how impossible it would be to know about them unless they were all noted in a Passport!

### **Making Passports can enhance relationships.**

One teacher said "*The staff and the parents like them and they seem to get much more involved than if it was just a report. It's a joint thing.*"

### **Passports are owned by the holder and family, not by the professionals**

Passports do not belong to the professionals who may have coordinated their creation. They belong to the person for whom they are created, and/or to their family or primary carers. It is these people who have the power to decide to whom the Passport is shown, how many copies are to be made and to whom they are distributed, and how they are used, generally.

Because consent has been obtained in advance from key people, using the Passports freely according to the needs of the situation cannot run into 'breach of confidentiality' problems.

### **Making Passports can be a way of training people to observe more competently.**

The process of planning and drafting new Passports is in itself a way of training staff (and by developing observation skills, Micheline Caldwell reported that the process of piloting Passport work at Sense Scotland revealed gaps in the knowledge that staff had of clients, and helped workers to make more relevant assessments. A teacher in a special school said. "*Trying to make it really makes you think. It's frightening*

*when you find out what you don't know."*

**Passports give a specific focus for discussion with families and staff, to enable deeper understanding of a person with special needs (and each other).**

Often, knowledge about a client with complex multiple disabilities is like a giant jigsaw; many people hold different pieces, but those people may never all meet to put all the pieces together into one whole meaningful picture. Often staff don't find out what they need to know about a person because they don't know what they don't know - and they don't ask the right questions. Families and carers often don't realise just how much they do know until someone asks them or shows them a 'starter page' of a draft Passport and says "is this right?" One family reported that now they are working on Passport development they prefer going to their daughter's Centre because now the Manager asks them things (and listens to the answers) and they can see from the Passport that their information is being used, whereas before, the Manager tended to tell them things about their daughter.

**How do I find out more about Passports?**

Contact Sally Millar at the address below:

- For a chat
- You may want to buy the £2.00 CALL Centre information pack on Personal Communication Passports (which includes a copy of the 1995 article from *Talking Sense*).
- You may want to get a copy of the CALL Training Leaflet which will tell you when the next Day Course on Passports will be held, in Edinburgh (or you can negotiate to have a presentation or a course on Passports held in your area or institution)
- Try and get a copy of "Personal Communication Passports: Guidelines for Good Practice". This new book, in full colour, outlines key principles of making and using Passports. It provides helpful examples taken from real Passports, created across the UK. This book is now available directly from CALL.

Check out the CALL Centre web site. In January 2004 there will be lots of Passports material available there.

**<http://www.callcentrescotland.org.uk>**

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