

# It's My Book

## Creating Ownership of a Communication Passport

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*This article was first published in Communication Matters Journal, No. Vol 18, number 1 (2004), following presentation at the Communication Matters national Symposium, September 2003.*

### WHAT ARE COMMUNICATION PASSPORTS?

Communication Passports were first developed by the CALL Centre in 1992. Passports are a means for clients to share important information about themselves with others.

The content of each Passport is personalised according to the needs of the user. They may contain information about the individual's family and friends, interests, strengths, likes, difficulties, communication skills, medical needs and nursery/school.

The information should be presented in a way that is accessible and interesting to all who are using it, therefore a mixture of writing, picture symbols, photographs or real objects can be used (Millar et al 1997).

### WHY USE PASSPORTS?

Brotherson et al (1992:513) refer to parents finding the repetition of information "frustrating and time inefficient". Passports offer a means of reducing both the amount of information that carers and parents have to share about their child and the stress attached to this.

The CALL Centre identifies that Passports are a way of supporting people during times of transition. The information contained in the Passport allows others to gain insight into the client, ensure consistency of approach during times of change and promote the development of relationships. The Passport itself also offers continuity and familiarity as clients take it into new situations (Millar et al 1997).

Passports can also be used as a framework for shared interaction: the content can help the client and conversational partners to initiate and maintain conversations and provide ideas for motivating topics of conversation. As one parent put it, "It's a way for him to open up a conversation."

### WHY INTRODUCE PASSPORTS TO JAMIE AND LEWIS?

The concept of Communication Passports was introduced to Jamie's family when he was three years old and Lewis's family when he was two. The rationale for developing the Communication Passports was to support the children's transition to nursery and facilitate shared interaction.

### DEVELOPMENT OF THE PASSPORTS

Families are essential to the development of Passports. It is the family that has the most intimate knowledge of their child and overview of all the services involved. It is this knowledge that sources the content of the Passport. The literature suggests that the support of families is crucial in promoting the success of AAC (Angelo 2000, Curry et al 2001). Therefore when developing Passports it is necessary to think about ways to engender the support and involvement of families.

When making Passports previously I had generally explained why a Passport would be valuable, collated information from the family and professionals involved and then produced a typed Passport containing relevant photos and symbols. The parents checked my production and then the Passport went into service. My concern was that this process seemed to dissociate parents from the Passport – it had been made by me not them and was perhaps perceived to be under my control and responsibility.

I wanted to increase the involvement of families. I hoped that by empowering them to create the Passport themselves, they would value it more and feel free to update and make changes to them when they wanted/needed to. Thus increasing their sense of ownership (Curry et al 2000).

For Jamie I attempted this by working on an individual basis with his mother. This involved explaining the role and value of a Passport, the possible content and the style in which it is written. Over a period of time his mother collated photographs and information. Eventually we both sat down at the dining table together and his mother designed and wrote each page whilst I cut and stuck.

At the time of developing Lewis's Passport I was involved with three other families who also required Passports. I therefore decided to use a workshop format. I felt this would be a more effective use of my time than individual sessions and would also provide parents with an opportunity to support each other. The idea of a Passport was introduced during home visits and

attendance at the workshop was discussed. Each parent was given a questionnaire to fill in and bring to the workshop along with any relevant pictures and photographs (Reilly 2002).

I discussed the workshop with the preschool special educational needs support service nursery nurses and teachers. They offered use of their facilities and help with the workshop. The workshop took a morning. Information about Passports was presented, examples of Passports used by other children shown and then the parents began making their pages. Once again the parents were the designers whilst the professionals primarily offered their laminating, cutting and sticking skills with occasional advice. Both parents attended a second Passport workshop in the summer term 2003. This was an informal occasion to enable parents to review their child's Passport, share ideas and access resources.

## THE SPIN-OFFS

The spin-offs that occurred from working in partnership with the parents are discussed below:

**Individuality and Ownership:** Millar et al (1997:2) state that "Passports are highly personalised and show the person they represent as human, unique and recognisable". Empowering parents to develop and make choices resulted in the production of Passports that reflected the individuality of each child and their family. This was evidenced in the varied content, layout and humour used in the Passports. I feel it is the language chosen by parents, their ideas, decisions and time invested that marks the Passport as belonging to their child and increases the parental sense of ownership.

**Responsibility:** Both families extended or amended their Passport when needed. For example Lewis's mother added a page when they got a new cat. During the spring term of 2003 myself and the preschool (SENS) nursery nurses discussed with both parents the need to update the Passports for school. I wrongly assumed that this process would need to be initiated by me. However both parents automatically assumed responsibility and began the process of updating the Passports themselves.

I believe that the initial manner in which the Passports were made enskilled the parents to do this and also fostered a sense of responsibility for the development of the Passport (Curry et al 2000). Involving the preschool SEN service with the initial workshop had positive implications for shared professional responsibilities:

They understood the rationale for using Passports with these children and consequently reinforced their use in the nursery environments. They also had more contact with the parents and nurseries than me and were able to provide resources and link with me regarding any questions or ideas that arose.

**Relationships:** I felt that the process of creating the Passports fostered positive working relationships between the parents and professionals involved. It also increased my understanding of each child's family life.

**Understanding:** The process of making and using the Passports has given the parents an understanding of how visual materials can be used to augment understanding and expression within daily situations and has increased their understanding of how the Passport can be used in the future.

**Advocacy:** Lewis's mother became an advocate for his Communication Passport. At a meeting she advocated its use in aiding his transition to school and explained to less knowledgeable nursery staff its role in supporting his communication.

**Measure of Change:** Both families discussed how the Passport, over time, has allowed them to see their child's development; as they removed old and added new pages they saw how their child's interests have changed.

## THOUGHTS FOR THE FUTURE

The use of each Passport at any given time varied according to the child's level of interest and also the needs of others. To ensure everyone is aware of how the Passports are being used, it would be beneficial if a review of them occurred at each multi-disciplinary meeting.

It is important to acknowledge that occasionally Passports may not be used or even forgotten; it relieves pressure on everyone if the success of a Passport is not based on its continual use in lots of settings, but on its long term maintenance, revival and survival. Perhaps investing in the process and working in partnership with parents is one way to achieve this.

## MUSINGS OF A PARENT

I am the mother of two boys – Jamie who is six and has Downs Syndrome and Euan who is four and who doesn't. Laura (Jamie's Speech and Language Therapist) suggested the Passport as a way of helping Jamie in his move to nursery school which he began at three. The nursery is mainstream and we were keen that the staff should have something to use with Jamie and which could also be used at home.

Jamie's communication skills were quite limited but the Passport gave us a tool to work with. It can be extremely discouraging as a parent when your child does not seem to want to talk to you and with a younger brother developing normally and rapidly alongside it was difficult to think of ways to help Jamie who didn't seem to want help.

We introduced a few Makaton signs to Jamie who, it has to be said, is pretty resistant to it. He thinks of himself as a talker and indeed, has sometimes refused to look at adults when they sign. Luckily the Passport has come to the rescue to help us to communicate with Jamie and for him to communicate with us. While all other strategies are ongoing, the Passport is the one thing that has engaged Jamie's attention. At first it went everywhere with us – to nursery, to Grandma and Grandpa's house and other visits. It was an automatic item in any packing – juice, wipes, snacks and Passport. We could bring it out to show visitors. Jamie had to sometimes be encouraged to join in at first but later he would always trot over to whoever had his blue book.

If Jamie was refusing to engage at all with me then I could bring out the Passport and we could look through the pictures in it together. I would "label", Jamie would turn the pages and although it might only last a minute or two – at least we were doing something together. Euan, his brother, also developed an interest in it and so the blue Passport was out a lot.

So far so good, but did it develop his communication skills any further? The proof came one day when Jamie was babbling frustratedly to me - he wanted something but couldn't ask for it. He marched away, got his Passport, brought it to me and opened it at the page for food. We had stuck a label from his favourite food on that page and Jamie pointed to it. I was delighted. It only happened once but it showed that he had made the connection between the flat label in the Passport and the tins of food which he eats and that he could refer to this source of information.

We used to use the Passport after nursery to talk about what he had done that day. Like a typical child Jamie always refuses to acknowledge that he had done anything at all at Nursery but at least we had something to look at together.

The main advantages of having the Passport have been the following:

- It allowed us to open up a dialogue with Jamie at a time when he was shutting down communication.
- It helped him to become familiar with some key words. For example, he has learned 'Mummy' and 'Daddy' from labelling photos in the Passport and not from calling us that to our faces. Once learned, he has transferred that knowledge and will call for us properly. The Passport was a stepping stone.
- It belongs to Jamie. After a while, Jamie stopped looking at the Passport. In fact he hid it after about 18 months of use. He got quite annoyed if it was produced at home so we put it 'on hold'. Maybe he was bored with it or maybe he felt it was becoming a task (and Jamie can sniff out a chore a mile off!). However, he was really pleased to see it when we brought it out again after Christmas 2002 and flicked through the pages, pointing and labelling grandparents. We are now updating the Passport to help with his transition from Nursery to P1. Jamie has to be involved with it to work.
- The Passport can pass on important information about Jamie to other people and my hope is that it can help to foster his relations with his peer group in Primary 1. For example, the news page which we will update every week might not mean a great deal to Jamie at first, but hopefully this will help with his inclusion – his peer group will know what he did at the weekend and he will have been part of the group. Jamie will still be communicating with his peers and whilst he might not know it, they will.
- I'm a great believer in using things that work when they work for you. The Passport is one tool. I can see a day when Jamie and I sit down to make scrapbooks together – maybe about going to the supermarket or about his day or somewhere he's been. Whatever age that happens at I think that it will simply be an evolution of the Passport process which began when he was three years old.

## MUSINGS OF ANOTHER PARENT

I am Mum to Robert and Lewis. Whilst in the euphoria of Lewis being born we were informed that he has Down's Syndrome. It was a shock, but one that was easy to deal with. We were given lots of help and advice, and Laura Coakes introduced herself to our family and built a good relationship with Lewis.

Parents try to help their child progress. That changes once you have a child with special needs, you spend more time and effort finding new ways to help. You also use the help and advice given from others, to the best of your ability, sometimes getting to the next level before anyone suggested. It's not easy. It does get difficult. There are frustrations for everyone, but when you reach that next level, it is one of the most enjoyable and rewarding experiences to have. Now don't get me wrong, when Laura suggested working on a Communication Passport for Lewis, my first initial reaction was "Great! Another job to add to the list". As soon as the concept was explained to me, I realised that this Passport could be really beneficial to him.

The workshop was not just another chance to socialise; it was an opportunity to find out about Passports. Sounds ridiculous, but to see an example is so much better than just talking about it. There were facilities at hand, ideas exchanged and help was given when requested. The workshop was informal and quite good fun. Most of all I went away with the knowledge that I am not the only one who is doing this very worthwhile 'job'.

We introduced the Passport to Lewis very enthusiastically. We all made a big fuss about it. Why? To get Lewis interested in it. It was also helpful that his Passport was personalised. Stickers of his favourite characters adorned the cover, catching his attention instantly. Lewis realised quickly that this was his book. He used it at first with immediate family, then family friends and finally with staff and children at the nursery he attended. As the pages contain pictures of people, places, items and characters that he knows well, Lewis used the Passport as a conversation starter, as a way to introduce himself.

Lewis's Passport was used frequently whilst at nursery, more so than at any other time. This was something he instigated himself. He chose to put his book in his bag before going to nursery. Watching him tell the other children who the pictures were of was incredible. This would then lead to question and answer sessions, for example, "What's your cat's name?", "Do you like biscuits?" With Lewis answering. Although Lewis used the same method with adults, it was easy to see that the adults gained more information about Lewis than the children. After using the Passport with him, most people realise the complexities that are Lewis.

There were (and still are) times when Lewis showed no interest in his Passport. How did we get him interested again? We used his favourite character. Thomas the Tank Engine was a Godsend and because he knows Thomas is in his book, Lewis will look through all the pages to find him, whilst talking about the pictures on the pages. Lewis's Passport has been updated to coincide with his move from nursery to school. Pictures of the school have been added, as have pictures of staff. This

enables Lewis to recognise his surroundings and the people he will meet, hopefully making this experience a little less daunting. Should his teacher or another member of staff ask a question that Lewis can't or won't answer, they will be able to refer to his Passport. Although not containing every detail about Lewis, enough information is held to gain some answers. Not only is his Passport invaluable to Lewis, it is beneficial for every one who knows or works closely with him.

Lewis's Passport has been, and still is, one of the best things I've spent time on, I realised quickly that it was not just another 'job', but a labour of love. Regularly updating it lets me see just how much he has changed, his likes, dislikes, favourite characters and his personality (some of the things that are gone in the blink of an eye). That's why we keep the old pages and pictures; to remind all of us how much Lewis has grown up and progressed.

So why not just have a photo album? Because your child's Passport is so much more than that. It's a door to a world of communication that can be difficult to open. It is a way for the individual to be heard when they don't have a voice. Most of all, it is exactly what it says it is; it is a Communication Passport.

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