

## 'Knowing the Child' – Personal Passports

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The population of children identified as having deaf-blindness is extremely varied, and now covers a very wide spectrum of etiologies and abilities and disabilities. Since the 1980s, because of changes in the nature of the population, deaf-blind specialists have found themselves working with more and more children who are at the very earliest stages of communicative awareness in their development, whatever their chronological age; indeed, in terms of communication a large number of them have only pre-intentional behaviors, doing things in response to what they are thinking or feeling but with no intention of trying to convey these things to another person. And their families may have good instinctive knowledge of the children but very little conscious awareness or understanding of what these children are thinking or feeling or wanting. The children's parents are often de-skilled and depressed and frustrated by the impact of the disabilities on the child e.g. very low affect, aversive responses, inconsistent responses, idiosyncratic responses, periods of ill health and regression, self-abusive behaviors, disturbed sleep patterns. Parents

also find themselves further de-skilled by the support services they receive—personnel from these services might be too directive and discourage personal growth or genuine collaboration, they might rely on inappropriate assessment approaches and so undervalue or even deny the parents' insights into their own child, the professionals themselves might feel inadequate to help and then convey this anxiety and sense of hopelessness to the parents, and they might further reinforce feelings of inadequacy in the parents by asking them for information about the child that the parents cannot possibly provide. Empowering parents in this challenging situation, 'humanizing' the child in other people's minds, and including everyone as a positive player in the child's developmental program can seem like an overwhelmingly tough prospect, but one helpful low-tech idea might be to develop a Personal Passport.

### Not enough information, or too much?

All too often children with deaf-blindness, and all the new people coming into their lives, are left to cope with all kinds of transitions with minimal preparation and very little accessible or useful support. At best there may be a few rushed words of explanation, or possibly a longer but nevertheless transient conversation. Maybe the child arrives accompanied by a folder of written information that includes medical reports, IEP documents, old evaluation reports, recommendations for further investigation, and correspondence regarding meetings and various other events. These stacks of undigested material offer little help to anyone searching for a quick and accessible guide to how the child operates, what they like, and how they communicate, nor relevant ideas about what to do if something appears to be wrong.

Even though the child may have had skilled and appropriate assessments of their medical, therapy,

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educational and communication needs, if the assessment recommendations are not picked out and organized in a clear and accessible way, and also translated into practical current advice on how to behave with the child, then they will be of little or no help to unfamiliar people who need to interact with the child in new settings. Even if they can be retrieved from the mass of written material, phrases like 'Tactile objects are Jenny's preferred mode of receptive communication', or 'Maria will need physical support to facilitate expressive signing', or 'It is important to alternate stimulating activities with those that calm throughout Tony's school day' are not helpful without further explanation that truly individualizes them for that specific child.

### **Some useful ideas**

There is a growing range of material aimed at tackling this challenge of turning assessment findings into practical and accessible guidelines that can be genuinely useful to newcomers in each child's life. 'Home Talk: A Family Assessment of Children who are Deafblind' (Harris, Hartshorne et al, 2003), is one of the most recent and most clearly organized. Also popular is 'Could you please tell my new teacher? A Parent/Teacher Guide to Successful Transitions' (Demchak & Elquist, 2001), which gives advice on creating a first transition portfolio for a child. Staff at the New England Center Deafblind Project (DeCaluwe et al) and Sharon Barrey-Grassick at the Senses Foundation Inc. in Western Australia are all doing innovative work on compiling video portfolios and communication guides for children with deaf-blindness. From a different angle, the whole Personal Futures Planning movement has had its own powerful impact upon how children with disabilities are viewed and how they are represented by others (see for example [www.allenshea.com/resource.html](http://www.allenshea.com/resource.html)).

### **Personal Passports**

Sometimes though, time is limited, urgency is high, and there is limited access to resources like video filming and editing equipment, multi-disciplinary teams, time and venues for team meetings, and people with Personal Futures Planning skills. Also, a simpler method that only requires a pen and paper, a ring binder and a few photographs, plus time for thinking and discussing, may be less daunting and more acceptable at the beginning of the process of 'knowing the child'. The Personal Passport idea came from two places simultaneously in the early 1990s—from the Sense Family Centre in London and from Sally Millar at the CALL (Communication Aids

for Language and Learning) Centre at the University of Edinburgh, who have produced a very useful article on Personal Passports ([http://callcentre.education.ed.ac.uk/Resources/Passports\\_REA/passports\\_rea.html](http://callcentre.education.ed.ac.uk/Resources/Passports_REA/passports_rea.html)). The Scottish Executive defines the idea in this way:

"The personal passport is a highly personalized and practical booklet or document written in a simple and direct way, which reflects the individual's personal style as well as supplying information, which can inform others about ways of ensuring comfortable and safe experiences for the child. The passport aims to create a highly positive view of the child and to stimulate more productive involvement of key people by encouraging awareness and confidence, shared knowledge and increased consistency of care." (Scottish Executive, 1999)

### **Heidi and her book**

One of the pioneers in this field was a six-year-old girl called Heidi. Heidi was very hard to "read"—in addition to her vision and hearing difficulties she had severe orthopedic disabilities, a high level of involuntary movements, a seizure disorder, she appeared to show no responses to any kind of sensory input, and was dependent on others for all her needs. Heidi's family felt that they had no idea about what she was thinking or feeling, or what she was aware of. Heidi's parents were asked to spend some time thinking about her likes and dislikes, and how they could identify these from the things that Heidi was doing. Even if they didn't know these things as hard facts, their guesses would be more likely to be correct than anybody else's guesses. They imagined a situation where they would have to leave Heidi with a safe stranger for a couple of hours with minimal time to explain anything—what would they need to write down about Heidi to give to the stranger so that Heidi and her new companion stood a reasonably good chance of having a happy time together? They also decided to write all this information in the first person and include photographs of Heidi so that the information would seem more immediate and personal (Goold, Borbilas, Clarke, & Kane 1993).

Four months later Heidi's parents had created ten simply but beautifully written pages, including photographs, that provided information on Heidi's likes and dislikes and the behaviors that she used to show these, plus information on some of her regular joint routine activities, all written in the first person. A huge change of awareness and understanding had taken place for Heidi's parents; four

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months after stating that they did not understand Heidi at all they were able to write things like:

*"I like holding hands, or having my hands stroked or clapped together."*

*"I love being massaged, but my feet are very sensitive."*

*"I like to sleep – I'm a snoozy girl!"*

*"When I am happy I will smile, giggle, hum (with my mouth open!), move my arms around more."*

*"When I am unhappy it will be quite obvious."*

They also included a 'Crying Checklist' that offered various possible explanations of things that might upset Heidi, ending with:

*"Being 'fussed' over – if it's not obvious, leave me alone for a few minutes and see if I can sort myself out."*

Heidi's parents reported various outcomes from the process of creating the passport:

- ❖ In order to begin the process they had allocated time specifically to sit and talk to each other for the first time since Heidi's birth six years earlier.
- ❖ They had their first realization that they actually knew Heidi quite well, and were interpreting her behaviors a lot during the day, and responding to her on the basis of these interpretations although they had never consciously realized that this was what they were doing. They reported that the quality of their interactions with Heidi developed rapidly once this initial realization had occurred.
- ❖ They first realized that some of Heidi's behaviors, in certain situations and circumstances, were probably intentionally communicative.
- ❖ They discovered for the first time that Heidi used different behaviors with them than with her younger brother, and that she was less expressive at school than she was at home.

In addition to the impact this process had on Heidi's parents, as a document Heidi's Book proved its power very quickly, raising awareness and encouraging more realistic expectations at her school, and particularly impacting positively at the hospital where Heidi went for regular planned medical treatments. Heidi's pediatrician asked all the involved medical and nursing staff on her hospital ward to read it, and during every hospital admission it was

kept at the foot of her bed along with all the usual charts for recording temperature, medication, bowel movements and so on. During Heidi's first hospital admission with the book, her mother reported that hospital staff asked all sorts of questions about Heidi's interests and likes and feelings for the first time, and she also noticed the staff actually speaking directly to Heidi for the first time she could ever remember. Heidi was reported to be the most settled she had ever been during this hospital admission, and when she got home she regained her normal sleep pattern faster than after previous hospital admissions, and her reflux was less evident also.

### **A powerful outcome of assessment findings**

This idea is a particularly useful outcome of the assessment procedure, because so often assessments of these children produce nothing of any practical help and may even be counter-productive, resulting in lower expectations of the child, and reduced self-esteem and confidence for the family. It helps to begin with seeking answers to the questions "What does the child like?" and "How do you know?" and "What does the child dislike?" and again "How do you know?" In this way we always begin at the beginning with basic issues of liking or not liking, wanting or not wanting. It is good to emphasize the process of creating the Passport rather than just the finished product, because it never should be finished unless the child dies, or becomes so fluent in language use that the Passport isn't needed any more. It is important to keep the document individualized, rather than issuing any kind of pro-forma outline where people just fill in the gaps with each child's name so every Passport is more or less like every other one, except for the name and the photographs. People may also need reminding that this is a Personal Passport not a Portfolio, which would usually be a more inclusive collection of information (e.g. Demchak & Elquist, and Harris, Hartshorne et al). Most of all the process offers a chance for growth by the parents and other family members, and maybe for professional staff too—seeing for themselves how much more they know about the child than they had previously realized, and also developing a different way of looking at and thinking about the child. Usually the child emerges from this process as more able and aware and competent than was previously thought too. This process might also furnish a genuine and specific focus for joint discussion between families and involved professionals, one with a direct practical outcome, and one in which the family have the prime access to the really in-depth information. After other parents saw Heidi's Book they produced their

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own, with a great variety of form and content and purpose in the Passports, sometimes with active contributions from the child and other siblings—some were very brief, some full of humor, some highly decorated, some packed with photos, some only concerned with the earliest levels of communicative awareness, but others describing tactile sign use and symbolic objects and daily calendars. All these Passports gave the reader the feeling that the children were right there in the room talking all about themselves.

### Concerns

There are several common pitfalls that cause people to lose their way as they create a Personal Passport:

1. developing a pro-forma and just leaving gaps for the child's name rather than truly individualizing the document (it should reflect both the child and the family who created it);
2. producing a document which does not have a loose-leaf format so it can never be expanded or updated;
3. being creative and esthetic (which is great), but making such a beautiful work of art that the family cannot bear to change it or to discard pages when they are not relevant any longer;
4. putting more and more into the Passport so that it becomes huge and moves beyond the area of communication entirely and has sections on medications, resuscitation procedures, daily routines, the IEP, the daily/weekly school schedule, a calendar of medical appointments, reports from doctors and other involved professionals, and so on. It is not meant to be a file of lots of information about the child—it is **mainly meant to be a portable tool to help comparative strangers quickly and easily know how to get communication (receptive and expressive) right with the child.**

There are relevant concerns about the use, accessibility, and updating of a Personal Passport, some of which are dealt with in the literature referred to, and in the CALL Centre pack. For example, it may be decided to update a Passport at agreed intervals of time, or update when necessary according to previously agreed criteria. Some families may prefer to update the entire document annually and keep each annual edition as an ongoing record of progress, almost like successive volumes in a lengthy novel. A parent told me that she often looked at the family copy of her son's Personal Passport at home

whenever he was having one of his frequent hospital admissions due to chronic health problems. She found this a great support during these difficult times "...because, you know, wherever he is and whatever he's thinking, he's always here at home with us when we read his Passport!"

### References

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#### If you would like more information

about Personal Passports and how to include this information in your technical assistance and/or training activities, please bring it to the attention of your child's/student's CDBS Service Coordinator.