Final Report
HEEKSS funded deafblind project

Contents

1. Introduction and summary of key findings

This project set out to provide two teams, each supporting a man who is deafblind, with tailored deafblind input from Sense, focusing particularly on the trainer supporting staff to develop new skills in-service. (Sense is a national organisation supporting people who are deafblind.)

Very sadly, one of the men, Tyron, who had very complex and rare health needs, became terminally ill shortly after the end of the project, and, after a period being cared for at home (in service), died.

Summary of key findings:
- There have been positive outcomes for the two clients concerned from this project (as observed by staff/managers, Practice Development Trainer, the Sense trainer and the mother of one client).
- Classroom based input on its own proved insufficient to enable a team to adapt its practice to meet the needs of someone who is deafblind. A combination of classroom based input, observation of practice/feedback and the trainer role modelling techniques when supporting the clients themselves had much more impact.
- The role of the manager proved critical in how, or the extent to which, a team takes new practice forward.
- Changing practice in a large team – so that new ways of working become embedded as custom and practice – is challenging and takes time.
- Consistency of approach was, and remains, a key issue. This is something that we will need to continue to work on post-project.
- Impetus/momentum proved very important – and challenging.
- Reliance on the one Sense trainer providing external training proved risky. Whilst his direct input to teams was very good and well-received, his absences (for very understandable reasons) created delays in the project and ultimately affected its momentum.
- Both services had an action plan (following the death of Tyron only one will now be working on this) and work on this (for Niles) continues post-project. This includes filming good practice and producing a Niles-specific deafblind induction pack.

2. Context and history

Brief synopsis of project:
This project set out to provide two teams with tailored deafblind input from Sense. The input focused on the specific needs of the two individuals and teams, based on the Sense trainer's observations of the staff working with the clients and his own experience of directly supporting the clients. It included a one day course for those who had not had this input previously, and in-service role modelling, observation and feedback as well as work with the managers and a Southdown Practice Development Trainer to enable them to take the work forward. The Sense trainer produced reports with recommendations for future work and we produced action plans from this. The intention was that this would mean:
- the men get more tailored, personalised, effective support
- the men are better able to understand/communicate because staff are better able to communicate with them
- the men are better able to understand/communicate about new experiences because staff are better able to develop the clients' communication skills (beyond existing communication)

- the staff team get more focused input tailored to their needs – and so are more likely to improve their skills and feel confident to use them

Southdown

Southdown is a housing and support provider based in Sussex. In our learning disability division 574 staff (including 100 bank staff) support 212 people with a learning disability in supported living, community outreach and residential services across Sussex. We have particular expertise in supporting people with complex needs, including autism, multiple/complex physical and learning disabilities and/or behaviour that can challenge. We have a strong focus on staff learning and development with an in-house Training Department (769 courses provided in 2016 – from induction to management development) and Positive Behaviour Support (PBS) team. See our website for more details: https://www.southdown.org

Context for the project

Southdown supports two men (in 2 services) who are also deafblind. (NB: Because there are so few people who are deafblind it could be relatively easy to identify these two individuals. As a consequence we have kept personal profile information – of both the men and the services - to a minimum in this report. The men's names have been changed.)

Service A: Supported living service. Just under 30 staff including a manager and two senior support workers. 5 clients in all – each with their own flat and with some communal space. Clients in this service tend to have complex needs and may present behaviours that can challenge. Niles, The client who is deafblind, moved in a few years ago.

Service B: Residential care service. Just under 25 staff including a manager and deputy manager. 7 clients who tend to have complex and multiple physical and learning disabilities. Tyron, the client who is deafblind, moved in a year before the start of this project. This team also had a member of Southdown's Positive Behaviour Support Team located with them for the duration of the project, supporting the team's work with the deafblind client.

Supporting these men effectively so that they can live the lives they want to live requires staff to have specific deafblind knowledge and skills. It requires careful thought and preparation – and a consistent approach.

Without effective support being deafblind can make it particularly difficult for someone to:
- Understand and make sense of what is happening now
- Understand what could or will be happening next or in the future
- Know whether it is day or night
- Communicate (including what they want/like/don't like and/or how they feel) and have this understood
- Understand what others are trying to communicate to them
- Make choices/decisions
- Have a conversation about more than the here and now and the merely functional
- Have a sense of agency and control
- Orientate themselves in, and safely find their way around, their environment – and, particularly, a new environment
- Prepare for new things in their life and have positive, new experiences
- Forge and maintain relationships with others
- Be actively engaged in their own lives

- Have fun
- Feel safe – but still able to try new things, learn, explore and develop.

There is a risk that those of us supporting someone with a learning disability can make assumptions about what that person likes/doesn't like, wants and chooses – and what their communication means. This is a particularly significant risk when we support someone who is deafblind.

Southdown provides a range of values-based training for staff (including Great Interactions, Person-centred Active Support, Positive Behaviour Support and Autism Spectrum Condition). This gives staff a good foundation for their work and the approaches/models we want them to use, but does not provide them with the specific knowledge required to support someone who is deafblind. For this, we have to commission specialist external input.

Accessing training that has an impact on practice
There are only approx. 33,000 adults (under 70 years) who are deafblind in the UK so training in this area is difficult and expensive to access. (Sense training costs us £750 per day, plus approx £100 for 1 nights' accommodation & expenses + £100 travel.)

At the start of this project there were two national organisations providing training; Sense and Deafblind UK. By the end of the project Sense had reorganised and no longer provides training externally, leaving just Deafblind UK. Local health services do sometimes provide training, but this is not provided regularly and we cannot access anything like sufficient places to train all 55 staff (plus new recruits). In addition, this local training tends to be generic (principles of supporting someone who is deafblind) rather than focusing on the specific needs of an individual.

Southdown had commissioned training from Sense for the two services concerned prior to this project (in 2013 and 1ˢᵗ quarter 2016 for one service and 2015 for the other). Given the cost of the training, staff turnover, the size of the teams and the need to staff the service it was impossible to ensure all staff had this input and only a proportion of each team did so. The trainer had information about the individuals concerned and tailored the training to their needs. The training was of good quality, well-received and some practice changed as a consequence, but this input did not have sufficient impact on practice. A more effective way of meeting the learning needs of staff was required and this project aimed to provide that.

3. The project methodology/inputs

Whilst those staff who had not previously attended training in supporting people who are deafblind did receive a one day training course, most of the input for this project was delivered in-service. The Sense trainer supported/interacted with each of the deafblind men himself (observed by staff), observed staff/client interactions and gave feedback, made suggestions, demonstrated the techniques he was teaching and gave staff the opportunity to practice new techniques with supervision from him. Although some staff had changed between the pre-project training and project input, there was a large group of staff who experienced both inputs, allowing some comparison of the impact of the different methodologies used.

The project had the following elements/inputs:

- Sense trainer met with managers of the two services, the senior manager for both services and the Practice Development Trainer coordinating the project to discuss the aims for the project and plan the subsequent inputs. As well as achieving agreement on the inputs, this enabled the trainer to engage the two Service Managers in the project.
- Sense trainer undertook two observations in each service – providing feedback to the manager and teams afterwards. He also directly supported the clients himself – to role model the techniques (as well as testing whether they would be acceptable to the clients)
- Sense trainer met with the mother of one of the two clients
- Sense trainer undertook a final observation in each service. He then met with one front-line manager, the senior manager and the Practice Development Trainer to give final verbal feedback.
- Sense trainer provided one training course for staff who had not had the previous training. This provided the theoretical input re being deafblind as well an introduction to guiding techniques.
- Sense trainer provided written material on guiding techniques and hand-over-hand support.
- Sense trainer produced final reports with recommendations.
- Managers of the 2 services, the senior manager responsible for them and the Practice Development Trainer met to create an action plan to take the work forward.

The Sense trainer who provided input is an expert in congenital deafblindness having worked in the field for over 15 years. He is currently undertaking a Masters degree in Deafblindness and Communication at the University of Groningen and was able to bring the latest research and ideas about good practice to this project.

The role of the Practice Development Trainers is significant in sustaining the impact of this project. They are not, however, deafblind experts and were the clients to experience significant change we might need to commission external input to enable the team to effectively support the clients with this. Despite Sense ceasing to operate as an external training organisation, we are able to commission the trainer direct to provide this input as a freelance trainer.

4. Evaluation methodology:

This project has been evaluated in the following ways:
- Initial benchmarking report from the Sense trainer noting his observations from the previous training he ran for these services
- Analysis of questionnaires completed by staff at the beginning and end of the project scoring their confidence in supporting the specific client in a number of areas (see appendix 2)
- Interim reports from the Sense trainer after his first observations
- Final report from the Sense trainer after final observations with recommendations
- Conversation between the Sense trainer and Tyron's mother (we cannot obtain feedback from the clients directly because of the nature of their disability)
- Discussion with managers facilitated by Practice Development Trainer once final recommendations received
- Observations of PBS Senior Support Worker allocated to Service B for the duration of the project until time of this report
- Observation by Practice Development Trainer of both men being supported by staff after project
- Sample interviewing of a small group of staff in both services by Practice Development Trainer.

5. Findings:

5.a Staff perceptions – 'before and after' staff questionnaire

This asked staff to self-assess (scale of 1-5) their confidence in relation to:
- Comfort in guiding the client
- Understanding the client's expressive communication
- Being able to explain themselves to the client
- Understanding of tactile signing

before and after the input from Sense.

Both services pre-input questionnaires scored an average of 14 out of a possible 25. Their post-input average scores were 19 and 19.5 out of 25, demonstrating an improvement in staff confidence. In addition, staff moved from an average of 3 out of 5 to 4 out of 5 in both teams re rating the service the team provides to the deafblind client. Staff interviewed after the end of the project cited examples of changes in practice and the subsequent positive impact on clients (see some of the quotes in boxes below) – as well as the challenge of understanding the communication of someone who is deafblind.

5.b Observations from Sense trainer following pre-project input (initial benchmark)

The Sense trainer reported a mixed response to his initial (pre-project) training input. Whilst many staff welcomed the input, he noted resistance from some members of the teams "…to the new knowledge and approaches that are recognised and established in the deafblind field." One example he gave was: "…the teams felt strongly that they could effectively guide a deafblind person while holding his hand, instead of using an established guiding grip used in the visual impairment and deafblind field. This grip enables the person to have more control over where they choose to move to and is encouraged. We have seen in Sense and in our wider work that some individuals are reluctant to make the transition to this grip, however we know that using a hand holding technique does limit the person's mobility."

He also noted that staff were very reluctant to make use of the concept of 'talking and listening hands' – as they struggled to see how this would be useful to the man they supported.

These observations informed the input provided as part of this project.

5.c Impact of change in methodology

The applied and kinaesthetic learning approach used during the project had more positive outcomes than the previous 'formal training only' approach. The Sense trainer noted that there was a

> *"I think [Sense trainer's] work with Tyron has been really helpful – it was good to see how he communicated with Tyron. I am getting more confident with using signs with Tyron and as a team we are looking to be more consistent in our communication with him."*
> Support Worker

"remarkable difference" between the two methods of delivery/inputs in "…the way staff accepted new ideas and concepts". The input was tailored to the individual clients and the settings in which the learning would be applied and could directly address staff concerns and practice. Staff were able to respond more openly and positively to new techniques when they saw the positive impact of the Sense trainer using the techniques in his interactions with the two men. A number of staff reported to the Sense trainer that the knowledge and skills being offered were "…far more tangible and understandable, when demonstrated first hand".

Those (established) staff interviewed post-project who had received the classroom based training only and had not observed the Sense trainer or been observed by him were less confident in using the new techniques and signing.

This is a significant finding – and appears to echo the findings of David Felce et al in a slightly different context; they found that classroom based training on its own did not sufficiently change practice re active support. Changes in practice that require a different conception of one's role and the consistent use of specific techniques that go beyond 'having a good heart' (may even seem counter-intuitive initially), may particularly require more than just classroom input. This is not to say that the formal classroom training input is not necessary. In this

> *"Spending time with [the Sense trainer] and seeing him support Niles has been really valuable. I can communicate better with him [Niles] using the hand-on-hand signing, helping him to explore more, taking time with things. It's been great. Niles seems more relaxed and happier."* Support Worker

project, the formal training enabled staff to really think about what it might be like to be deafblind – and to (as some said) have their 'minds blown' by this. Our finding is that the training is necessary, but not sufficient, to significantly change the practice in a service in this area.

The effective learning of a new approach/skill requires six stages:
1. Awareness and understanding (that there is a different approach/technique, the theory behind this and that one's practice needs to change)
2. Knowledge of the specific practical skills and techniques required – and an opportunity to practice these
3. The confidence and support to try the skill/technique in one's work
4. Consistent application of the skill/technique
5. Reflection on how this has gone and what one might do differently next time
6. Reinforcement in the system for using the new skill/technique (this can include feedback from a manager or feedback from the client that the technique is working - e.g. from their reaction)

Classroom based input can only provide the environment for the first three of these stages (and possibly the fifth if there is a follow up session) – the rest have to happen in-service.

It is important to note that the input worked so well in part (largely) because of the skills of the Sense trainer. He engaged staff extremely well, demonstrated an understanding of their perspective, was respectful and everyone reported that his manner was friendly and approachable. This, combined with the evidence of his skills when he interacted with Tyron and Niles, meant that he was able to suggest new ways of doing things and 'challenge' staff beliefs/practice in such a way that many staff were able to make changes. His interactions with the 2 men gave him very important credibility – he could demonstrate that what he was suggesting worked.

5.d Specific changes in practice/positive outcomes for clients observed by Sense trainer

> *"Using 'hand under hand' with Niles to help him find/explore things has been very useful."* Support Worker

i) Sighted guide technique – the Sense trainer demonstrated this technique with the two men and taught some staff how to use it with them (having also demonstrated this on the formal training). He noted practice improvements once these techniques were introduced, with the clients having more control/agency when staff used this technique. Services will need to continue to focus on this to ensure this technique is used consistently by everyone.

ii) 'Talking and listening hands' – some staff in both teams were trained in this approach and were receptive to it, having struggled with the concept in the pre-project training. This included being shown and then practicing under supervision (from the Sense trainer) 'turn taking', with tactile sign language and different hand positions for talking and listening. There is more work to do to ensure that this is used consistently in both services – and this has proved to be the area where further input may be required, as this is the most 'technical' skill taught and learnt.

iii) Conversations – in the initial stages of the project the Sense trainer noted that 'conversations' between staff and the deafblind men focused purely on 'instructional information' and were always in the context of the present. Tyron had more limited expressive communication and staff tended to apply literal meanings to this – and perhaps made assumptions about what he might mean. The input from Sense challenged this and encouraged staff to be less definite/literal and develop a wider interpretation of the clients' communication, which some staff responded to positively. This remains a work in progress. The Sense trainer recommended that staff are
> *"…reminded, challenged and encouraged to develop their thinking further on the notion of expressive communication and its many meanings (declarative, imperative etc)"*

iv) Initially staff in both services supported the clients by doing more for them and bringing things to them. This was done with the best intentions, but made it harder for the two men to make sense of their environment, be actively involved in their own lives or have a sense of agency. The trainer encouraged staff to support the client to be involved and find where things were and go and get them. He then observed staff doing this.   Again, this is something the teams will need to continue to focus on and develop further.

> *'Tyron seems more settled and seems to be communicating a lot more. It's hard to know what he is signing/saying but we are getting better at that and I think he's more outgoing as a result."* Support Worker

v) Tyron responded well when staff used the new techniques consistently and appeared visibly more relaxed (to the Sense trainer and staff) as the project progressed

vi) Niles responded well to staff using 'listening and talking hands'. The trainer noted that some staff became skilled at giving information about what is happening and his choices – so the 'talking' aspect for the staff and the listening' aspect for Niles. The next step is to develop this so that staff do more listening and Niles more talking.

5.e Changes in practice observed by service managers and PBS senior:

i) ***Slowing down and enabling the client to explore his environment:*** Manager of Service A observed that as a consequence of the input, staff seemed more comfortable in taking their time with Niles. This applies to both their communication with him and also with helping him to explore his environment instead of bringing everything to him or placing it within his immediate reach. There was a sense of 'slowing down' and Niles seemed more relaxed as a result of this.

ii) ***Communication & rapport:*** The managers of both services said that they had been working on introducing more objects of reference for each client for activities and as time references (e.g. food trays, car keys, shoes etc). It is conceptually hard to think about what would be relevant as an object of reference for a person who has been deafblind from birth. For example, giving someone a smaller version of something is not useful if they have never seen the real-size thing. This will continue to require some thought from the teams.

> *"I went for a walk with Tyron in the forest and gave him a pine cone to hold which he seemed very interested in. I told the staff about this and …they said they had tried the same thing a week before. So now we can use a pine cone as an object to represent going for a walk in the forest. It's good to know we are on the same page about these things"* Tyron's mother.

The manager of Service B reported that they have focused on developing ways of helping Tyron to have a time reference. Some staff in this service had become confident signers with Tyron, and the PBS specialist located in the team noted increased rapport between staff and Tyron and that he is signing a lot more with staff. She commented that Tyron had become much more expressive in his communication as a result of these interactions. The service began developing a communication folder of relevant signs and objects of reference for Tyron. In addition, the PBS senior noted that staff were more responsive to Tyron and asking each other 'what does this sign mean?' or 'how do you sign…?'

5.f Changes in practice observed by mother of Tyron

Tyron's mother noted a number of changes as a consequence of the project.

She said: "When Tyron first moved in the staff did not have experience in supporting someone who is deafblind but I was struck by the fact that they wanted to learn and respond to him. So the general training was important to give them that background information and then the [project] support that was Tyron-focused worked really well.

I now see staff signing with/to him [Tyron] – letting him know what's happening, trying to work out what he is saying with his funny little gestures and rituals. They are very responsive to Tyron and his needs. They take their time with him and seem keen to learn from him.

They have been trying to do some of the things [the Sense trainer] recommended – e.g. objects of reference... It's good to see staff trying things out with him. The training and the work done by [Sense trainer] has been really worthwhile. The staff have always been responsive to Tyron but the [project] has helped them to understand the needs of someone who is deafblind a lot more and this has helped Tyron to build trust with them, to feel more secure and to not be so isolated.

I have always been happy with how the staff support Tyron and the [project] has helped them be even more responsive."

5.f Observation by Practice Development Trainer (after end of project)

A Practice Development Trainer observed both Tyron and Niles being supported by staff after the end of the project to check that good practice was being sustained.

Re support offered to Niles in the morning and on the way to the day centre she commented:

"Niles able to make his breakfast (cereal, milk, custard and fruit) and choose a drink with touch support. Carried his tray to the table. Ate independently, but staff member was available within reach if required. Signs used to tell Niles that he was going to the day centre on his bike.

Supported to ride his bike at his own pace.

I was impressed by the positive communications between Niles and the staff member. Staff did not try to take over, even with the trickier tasks, such as pouring milk. Just enough support was given to enable Niles to complete the task successfully. Niles was in control of what was happening at all times."

Re support offered to Tyron in the morning she commented:

"Responded positively to jokes "cheeky man". Signs for more, yoghurt and finished – ensured that Tyron chose when to finish breakfast. He changed his mind a couple of times! Tyron asked to go to the toilet – staff responded with signs and immediately supported him to go to the bathroom."

5.h The role of the manager

The role of the manager proved critical in how, or whether, a team takes new practice forward. When managers drove the project work and emphasised the importance of changing practice, we saw practice change in the service. If managers were absent, or focused on the difficulties staff were experiencing, staff were more able to stay with older ways of working. This is in the context of services being under pressure due to the needs of the individuals being supported and recruitment issues.

5.i Consistency

Consistency of approach was, and remains, a key issue. This was highlighted by the Sense trainer in his final report. There are challenges in ensuring input such as this reaches all staff in a team of 25-30 staff in the time available in the project - and is sustained. The Sense trainer was not able to observe or work with every member of staff, although he had contact with a larger number via the feedback sessions in team meetings. Within such a large team, there are inevitably staff who have adopted the new ways of working and are using them more consistently, and others who will need support/guidance to do so. As the Sense trainer noted in his final report:

> "*Both [services] employ key staff who are exceptional in their practice and demonstrate sound intuition in understanding deafblind communication...Additionally both services, at the time, employed staff who adopted a more out of date approach to supporting deafblind people. They retained a more entrenched view that their old approaches to supporting the men were working and that change was not needed.*"

To address this issue, services took forward the Sense trainer's recommendations that:

- each service should have a smaller staff team of 'specialists' (selected for their competency and willingness to develop communication and practice with both men) within the wider team who are always scheduled on the rota to support Tyron or Niles. 8 of these core staff plus the PBS senior have signed up for an online BSL course as these are the signs Tyron and Niles have been taught (as children)

- Tyron and Niles should have a more consistent routine to help them make sense of what is and will be happening

- Services should film those staff who are confident/skilled at using the techniques taught and use film more widely to review interactions and explore what the men are communicating.

The service action plans also include other actions to improve consistency and ensure good practice is adopted and more likely to be sustained/embedded. This includes ongoing support from the Practice Development Trainers (including supporting the development of induction materials). Staff with good skills in supporting Niles are being filmed so that this practice can be spread amongst the team and shown to new starters.

Whilst consistency is a real issue, a new member of staff interviewed who was recruited after the end of the project talked about learning and becoming more confident by observing the staff who were using the new techniques and signing – suggesting that some of the practice is spreading beyond those directly observed/observing.

5.j Impetus/momentum

The project was beset with delays. On two occasions the Sense trainer became ill whilst with us and had to leave early and on a third a Southern Rail strike meant that we had to cancel his visit altogether. Whilst everyone was understanding, this was unfortunate for services that had had to work hard to organise rotas to maximise the input. All the missed visits were rearranged. Whilst we were waiting for the final report from Sense, the trainer's personal circumstances meant that for very understandable reasons he had to have a period of time off work and in the meantime Sense restructured. This led to a long delay before we received the final report and recommendations. In the meantime, the manager of one service was promoted out of the service and the senior manager for both services left Southdown. In accommodation-based services it is difficult enough to sustain momentum with shift patterns, turnover, having to respond to immediate client needs/crises etc., without the additional hurdles the project created. Managers reported that they felt that the project 'stalled' at this point, and the loss of momentum made it harder to sustain the changes in practice (and may have made it easier for more resistant staff to slip back into previous ways of working). The momentum has picked up again since we received the final recommendations and produced an action plan, but will take more work to sustain than would have been the case had the original timescale worked. With hindsight, it might have been helpful to have considered at the outset what we might do with these kind of hiccoughs – and whether there was any additional 'home work' that could be set in the meantime. We had very little option re seeking alternative input, given the specialist nature of the input, limited choice of provider and relationships the Sense trainer had established.

6. Recommendations:

- Services that are not deafblind specialists who support/start to support someone who is deafblind should consider commissioning a package of training and support for their staff, with some classroom based input but a focus on observation/feedback, role modelling and support in-service from someone with expertise. They should not expect classroom based training on its own to enable staff to sufficiently develop and apply skills or change practice

- Services with larger staff groups should consider having a core team that provides most of the support to the deafblind individual, to improve practice and consistency. Staff selected for this core group should have demonstrated an aptitude for/openness to learning and using the required tools/skills, in addition to having good rapport with the deafblind client

- Managers need to be prepared for the project and supported/expected to lead the work in their service – with a focus on maintaining momentum and the work, overcoming resistance and

reinforcing good practice. Meetings with the managers helped this process, including by providing a requirement to feedback on progress to a group/senior managers/external trainer. Sustaining the work during more challenging times in the service and post input requires particular focus.

- Consideration should be given to involving family members more fully and at an earlier stage. Whilst the Sense trainer managed to speak to and get the views of Tyron's mother, the disruption to the schedule meant that he was not able to speak to Niles mother. Niles' mother is supportive of the post project work to film her son being supported to develop staff skills and positive about the team having deafblind specific training.

- A regional network for services/champions supporting people who are deafblind would be helpful. This could enable services to learn together and share both good practice and the costs of training and expert support.

7. Conclusions:

This project has enabled two services in Southdown to develop further skills and change practice to more effectively support two men who are deafblind. There have been some clear, positive outcomes for the clients and staff teams concerned. Managers and many staff have valued the input and report that it has made a difference to their practice and confidence in using required skills. At the same time, this is very much a work in progress. There is more work to do to spread the skills, knowledge and practice across all staff in both teams and ensure that the new good practice becomes embedded, is used consistently and sustained. The focus this will require is not insignificant. Developing/changing practice and embedding this, particularly in a large team, takes time and effort. Some areas (e.g. 'talking hands') may require additional specialist input. We are exploring the option of linking up with specialist services in our region and a Practice Development Trainer will be visiting a Sense service to observe practice there. For the most part, however, the work required will be reflected in the action plan created and has already begun.

One of the main findings from this project is that classroom based training for this type of learning may not be sufficient to change practice. Support in-service (modelling, observing, giving feedback) has proved much more effective in enabling staff to adopt new ways of working and change their practice. Supporting those staff who find this more difficult is the next challenge.

Finally, we'd like to finish with the words of Tyron's mother. She sent the following email to the team after Tyron's death (and has given permission for us to reproduce it here):

> *"Thank you for everything you have done for Tyron (and me). You are all amazing and deserve far more recognition for what you do and the commitment and love you give to all those in your care."*

We would like to thank HEEKSS for the funding that enabled us to do this work.

Jenny Spaull, Training Manager June 2018
Tel 01273 405809
Email: jenny.spaull@southdown.org

Further references:

Sense *https://www.sense.org.uk* This website contains a range of resources useful to those supporting someone who is deafblind.

Deafblind UK https://deafblind.org.uk

For more information about this project, please contact Jenny Spaull: email jenny.spaull@southdown.org or tel 01273 405809

Appendix One

Underpinning theoretical approach to communication at Sense.

Sense use 'Total Communication' approach to support individuals with complex communication needs. There are many influences to our practice at Sense and leading practitioners continue to steer the way in which Sense support people to make connections and communicate.

Professor Jan van Dijk, prior to the 1990's, designed the 'total communication approach', an approach using objects of reference, gesture, pictures and symbols to support sign language. This approach remains a fundamental foundation for the development of language.

In the1990s the European working group carried out research to try to develop new approaches as the total communication approach was not working and congenitally deafblind people were not developing language, especially expressive language. In1996 the Deafblind International Communication Network was first set up, organising conferences and courses across Europe. More recently this group has set up a European Masters course on Communication and Congenital Deafblindness at the University of Groningen.

In1998 / 1999 Sense completed a research project looking at the value of imitation in developing social interactions and expressive communication in congenitally deafblind people living in Sense residential services. In 1999 Anne Nafstad and Inger Rodbroe published "Co-Creating Communication: Perspectives on Diagnostic Education for Individuals Who Are Congenitally Deafblind and Individuals Whose Impairments May Have Similar Effects", turning the research into theory and concluding that **it is never too late** to try a new approach – once you find the right one it doesn't take long to work.

In 2006 – 2008 four booklets on Communication and Congenital Deafblindness, based on the work of DbI's Communication Network, of which Sense is a member, were written to support and inspire the networks around each person with deafblindness. The target groups for these booklets are parents and professionals in contact with congenital deafblind children and adults.

In addition leading works of McInnes and Treffry, Helen Bradley, Lile Nielson, Nind and Hewett, Barbara Miles continue to influence and shape the communication approach at Sense.

(Information provided by Sense)

Deafblind Awareness – Questionnaire

Your name:…………………………...   **Today's date…………………….. **

Service…………………………………...

PART ONE – Learning and Development

1. Please indicate below what deafblind training you have previously had and where you feel you have gained your knowledge and skills (you can use another sheet if necessary)

> **Comments:**

2. In your own words – what are you hoping to get out of the Sense input and mentoring?

> **Comments:**

3. Do you have any concerns about the input and mentoring?

> **Comments:**

4. What difference to [client name] do you hope the input / mentoring will make?

> **Comments:**

PART TWO – Confidence Questionnaire

The following questions are to be answered now and then after receiving some further input and mentoring in regards to supporting a deafblind person in your service – **at this stage please just fill in the column on the left.**

Scale: 1= Low and 5 = High

Today						After the input / mentoring				
1	**2**	**3**	**4**	**5**	How comfortable are you with **guiding James**?	**1**	**2**	**3**	**4**	**5**

Now think about specific aspects of **communicating with [client]**. (Note that 1= Low and 5 = High)

Today						After the input / mentoring				
1	**2**	**3**	**4**	**5**	Understanding what [client] s is saying through his expressive communication	**1**	**2**	**3**	**4**	**5**
1	**2**	**3**	**4**	**5**	Being able to clearly explain yourself to [client]	**1**	**2**	**3**	**4**	**5**
1	**2**	**3**	**4**	**5**	Understanding the principles of tactile sign language	**1**	**2**	**3**	**4**	**5**

If you were to really honestly rate the *service* your team provides to [client] - what would that rating be?

Today						After the input / mentoring				
1	**2**	**3**	**4**	**5**	If you were to really honestly rate the *service* your team provides to [client] - what would that rating be?	**1**	**2**	**3**	**4**	**5**

Any additional comments (today)

Any additional comments (after input/mentoring)