



Picture Exchange Communication System (PECS) Report, Nov 2018



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Communication and Learning Disabilities

One of the most distressing and frustrating issues when working with people with learning disabilities is the inability to communicate.

A profound and multiple learning disability (PMLD) is when a person has a severe learning disability and other disabilities that significantly affect their ability to communicate and be independent. Someone with PMLD may have severe difficulties seeing, hearing, speaking and moving.

Optima Care

Optima Care provides residential, supported living and transition services for school leavers and adults. We also provide specialist support for elderly individuals with LD, including end of life care. We support people with severe/enduring mental health conditions and intellectual disabilities with complex needs.

The Shine therapeutic model of care was designed by Optima Care to ensure that people of all ages with learning disabilities and complex needs, including severe/enduring mental health issues, realise their full potential. Underpinned by a clear support framework with milestones of personal goal achievements, Shine may be tailored according to individual need. It helps to ensure a transition journey through our services towards more independent living.

Our services

Within Optima Care's Kent region we support people with varying degrees of abilities and needs ranging from intellectual disabilities with complex needs to active support in an independent living setting. We run 12 separate services ranging from 1 person living alone, to 20 individuals living together in their own community residential setting. These services operate under one of the following three broad headings:

Young adult transition services

Our transition service offers 2 – 5 years' person-centred pathways for 18 – 25 year olds. Pathways are developed in line with an individual's Education, Health and Care (EHC) plan and designed to help young people transition into adulthood – and Supported Living – with a sense of confidence and optimism.

We believe that everyone should be afforded the opportunity to make informed life choices and to safely explore and nurture their individual talents, interests and possibilities.

Supported Living

A member of the Housing & Support Alliance, Optima Care partners with Registered Social Landlords to provide tailored accommodation and support. Our expertise spans autistic spectrum conditions, total communication and behaviours that challenge. We also offer Enhanced Supported Living.

High acuity community living

We have separate centres of excellence focused on two key areas of specialism: Total Communication and Step-Down Pathways. Optima Care is unique in offering support by an in-house multi-disciplinary team within a community environment. Our Shine model of therapeutic care provides the framework.

Optima Care supports the Transforming Care agenda, helping people move out of secure settings and into the community, improving life skills, independence and quality of life – enabling family and loved ones to be very much involved – whilst reducing the cost of care to Local Authorities.

The PECS experience: our staff and people we support

We advocate continued learning and development for all our employees – this is also provided within our Shine, which details our workplace values. All our staff follow a Person Centred Approach and they receive ongoing, specialist training in this regard. This includes effective communication, Person Centred thinking and pathways planning, Active Support and Therapeutic Management of Violence and Aggression.

Our staff are constantly striving to find the best and innovative ways to help individuals communicate their needs: we advocate that “Challenging Behaviour is unmet needs”.

Makaton and British Sign Language are commonly used but many of our service users don't have those languages, therefore 'trial & error' is often the norm.

This is from a front-line Team Leader:

“I have worked in the care sector for approximately twelve years and one of the constant struggles that I have faced is an ability to communicate effectively with service users who have difficulties with verbal communication.

The struggle is real. How do I know what someone wants? How can I be sure I am doing things right? Am I meeting the individual's needs? Or am I helping them achieve their goals and aspirations?

I received training in basic Makaton. This was not easily accessible as the cost of Makaton training is high and therefore I was only taught basic skills to help communicate essential tasks or needs. The use of symbols and flash cards would assist with some communication but it still caused barriers and led to frustrations and individuals displaying behaviour that challenges.

When I began working for Optima Care it was clear that they were focused on providing services that were not restricted by barriers in communication. I was introduced to new ideas and different techniques on how to communicate with individuals. It still was not enough to be able to maintain a consistent approach to communicating with those who struggled to verbalise or sign.

When two new service users arrived who were still at school, they had PECS [Picture Exchange Communication System] books. At first these books looked similar to our flash cards, they just had the pictures/symbols held in place with Velcro. No-one explained how these books worked. We tried encouraging the use of the books, we would try to point at the pictures, offer different choices with the pictures or refer to the books constantly with little input from the individuals. We were failing.

We asked the school for help. Their own Speech and Language Therapist attended our service and explained and demonstrated how to use the PECS books. This did not go as well as expected because the individual displayed behaviour that challenged and the therapist had to reschedule. With family visits and school holidays it took a while for the therapist to be able to return. The next visit was more successful and after a 15-minute chat and small demonstration we now had a basic understanding. The individuals we supported could now ask us for specific food and drink items instead of just accepting what we offered. They could ask for certain activities, but we could not help but feel that PECS was still limited.

We had discussions in staff meetings and contacted our HR manager who began sourcing more information. It was identified that the providers of the PECS programme would come to our service and deliver training but the cost of this training was prohibitive. But then we became aware of HEE who agreed to support our PECS project, hence funding was provided to support the training of 20 staff members on PECS.

We initially thought that we would need perhaps a full day's training but were surprised to learn that it would take a full 3 days so there was a lot more to PECS than we first imagined.

Training day arrived and we were all shocked when we realised that we had been delivering the exchanges of communication incorrectly. It was agreed that we would start from scratch. Laminators became our new best friends. So many symbols and pictures were printed to the individual's required size. The entire environment became PECS accessible. There was not one place where an individual would not be able to communicate effectively. So now we just needed to be consistent and encourage the use of PECS rather than resorting to the guessing game we were all used to.

That was harder than it sounds. When you can open your mouth and speak it is completely unnatural to be silent. However, this was needed if PECS was going to work. I spent weeks reminding staff "don't speak", "stand by the book". Finally, we started to see individuals using sentence strips, schedule boards, now and next cards. Individuals who would display behaviour to gain things were now handing us strips that read "I want...".

It's working, incidents decreased and participation and engagement increased. It was now time to filter it to our neighbouring service. The individuals who resided with us were older, ranging from 30's to 70. Some of the individuals were already verbal but they too improved with the use of PECS. Activities they had never displayed an interest in were being requested after seeing them in the book. PECS could be designed to aid understanding of health appointments, care reviews and so on. The individuals we support were now fully able to communicate and this greatly improved their quality of life.

One young lady has used PECS to aid her verbal skills. She can now verbalise complete sentences. It has greatly improved her relationship with her mother as there is now an understanding of what is being said.

Goals and aspirations are being achieved, life skills improved and independence continues to be promoted.

Without the funding for the training from HEE, it is likely that we would still be experiencing barriers with regards to effective communication between the individuals we support and the staffing team."

Zoe Lamb – Team Leader – Optima Care Ltd

From a Support Worker:

"One of our young people uses PECS to form full sentences and has not displayed any incidents of challenging behaviour in over 4 months now. I believe it's all down to using PECS. Before he would constantly show aggression, always appeared to be unhappy and looking sullen, keeping to himself and not engaging with any of the other service users.

Now, he's a different person. He carries his PECS book around with him all the time and has no problem letting people know what he needs or how he's feeling. He's currently a very happy person. Imagine being closed in a small dark place for as long as you can remember and then suddenly the door to the rest of the world is opened and you're free!"

A testimonial from a parent:

"My son is so much happier and calmer now. The staff are brilliant. They have really got to know him and jelled with him. Although he isn't able to speak, he communicates using pictures. He now gets out and about a lot. They've really helped him become more independent."

The process

I'm Christina, the Training Manager at Optima Care, I became involved with this project when the HR manager (Nikki) tasked me with finding the promoters of PECS and how much they would charge us for coming to our site and training our staff in the use of PECS.

I guessed that the training would be expensive as the system was probably copyrighted, but was still shocked to learn the exact amount. Nikki and I agreed that it was too much so I spent some time trying to find alternatives. In the meantime Nikki was made aware of an offer of funding innovative staff education and training projects via the Intellectual Disabilities Programme then working across Kent, Surrey and Sussex in Health Education England. We thought it was worth a shot and applied. We were both amazed and delighted that our little project was accepted by HEE and I set about facilitating the training. The PECS people would come to our site and train a maximum of 20 staff and the training would take 3 days. At the time we had different premises and had the luxury of having our own training suite, which cut the costs somewhat, but it was still going to be somewhere in the region of £7,500 plus. However, the training was very good and all the delegates said they had gained a huge amount from it in terms of skills and knowledge and were really looking forward to putting it all into practice.

In a very short space of time the positive effects on the people we support were quite dramatic. People who were previously unable to communicate in any way were learning to "talk" and it was evident that they were happier in so many ways. Staff were able to identify preferred activities which hadn't even been thought of before. Certain foods, which the staff thought the people we support liked, were now being passed over in place of others. Even small things like that can make a whole world of difference to a person. I cannot even begin to imagine what it would be like to be locked in your own head.

So, what next?

Because of the huge success at our 'Gate House' site, we naturally will be cascading the system down to all the other services that support people with Autism and / or Learning Disabilities: those individuals who are unable to communicate verbally or who have difficulty communicating in any way. With the help of colleagues who have knowledge of PECS, I intend to develop a training programme encompassing Makaton and PECS. This will also focus on the difficulties that people with Autism, Asperger's and other Learning Disabilities have with regards to communication.

At Optima Care, we have pledged to do everything we can to help the people we support to gain as much independence as possible. This naturally includes communication skills.

What is the Picture Exchange Communication System (PECS)?

PECS allows people without the ability to speak, to communicate using pictures. Originally created for use by those with Autism, the system can also benefit individuals with a wide range of Learning Disabilities.

PECS is used by many special needs schools but not all of them. Some might use objects of reference, sign language and Makaton instead. Equally, most community residential services don't have any formal communication systems in place. This lack of a standardised system - coupled with poor liaison around communications between schools and health and social care services - means that when individuals are transitioned from school or college to community residential services, this learnt knowledge can become lost. An inability to communicate leads to frustration and this can be exhibited through challenging behaviour, including self-harming or aggression towards staff.

Health Education England (HEE) Intellectual Disabilities Programme

Back in October 2017, two HEE representatives from the Intellectual Disabilities Programme working across Kent, Surrey and Sussex visited Optima Care's Gate House, our service for young adults who have recently left school or college, to see PECS in action. The visit came following funding that the service was provided with by HEE earlier that year, to support the training of 20 staff members on PECS.

HEE put out the funding offer across the health and social care sector – including doctors, hospitals, schools, elderly care etc – all of which could then opt to respond with a case for why they should receive the support. HEE then decided upon 20 very individual projects that spanned all these sectors, based upon what they thought would benefit the region most.

The two HEE representatives spoke with staff and managers to gain feedback on PECS and discuss next steps for the training programme.

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