

Opening up Children's Lives Through Interaction and Communication

In August of this year I was lucky enough to receive funding from the EU and North-West Universities Association's 'Leonardo Da Vinci' staff exchange scheme. I made a week's trip to Fundatia Casa Luminii, having been invited by Sarah Parry. The Centre is run by a dedicated husband and wife team, Sandu (Director) and Alex Micu (Programme Coordinator). Alex has put together individualised programmes for the children covering the areas of cognition, sensory and motor development, self-care, language and socialisation. One of the things that struck me about my visit was the stigma that is attached to disability - people with disabilities are even referred to as 'the deficient'. Unfortunately, there has been little change in the annual numbers of children with disabilities who are abandoned, so the number of children and young people requiring care continues to rise.

Only a very small number of children with disabilities were fostered when the orphanages closed, there are currently about 80 children who live in Slatina's government apartments in groups of 6-8 children (often with complex and challenging needs) with 2-3 carers working on a rota. The carers are often ex-orphanage staff. The provision that I saw varied greatly in quality. One apartment had very tidy and presentable (obviously child-free) 'public' rooms, whereas the bedroom to which the children had been confined (largely unsupervised) was trashed. One child in particular was extremely agitated, displaying repetitive, stereotyped and sometimes aggressive behaviours. A visiting nurse was prescribing sedatives, the standard treatment for challenging behaviour. The children were desperate for attention, immediately swarming to us and pulling us into the bedroom to play. I must admit that I found it difficult to tell the difference between boys and girls as they all have their hair cropped. Another child we met from a different apartment was very solitary, engaged in self-stimulatory behaviours and self-harmed through severe head-banging. He had clear rope-burns on the inside of his elbows and backs of his ankles where he had been tied down, which was distressing to see. Alex and her staff are doing their best to advocate for the children and stop this abuse of human rights happening. She has taken this particular child numerous times to the Child Protection Office with clear evidence that he has been tied down (one time he arrived at her centre with the rope still around his ankles), but nothing has been done, the care staff have managed to talk their way out of it every time. This is a child of 10 who couldn't walk when he first started at Casa Luminii; the staff at the centre taught him to walk and his care staff did not even notice when he reached this developmental milestone. Gladly however, not all of the carers exhibit such disinterest. One apartment I visited was noticeably different, with toys available, children's pictures on the wall, bedrooms that looked like children's bedrooms and children who were well-dressed. The carers from this apartment joined us in taking the children out to the park and spent time playing with them. This gives me heart that there are residential staff who care and are willing to work with Alex and visiting specialists to improve children's quality of life.

When I visited there was a group of approximately 18 Medlink students staying and working at the centre. They made an impressive workforce who were very keen to learn. On day one, I gave the students a briefing session and a template so that they could each write a communication passport (Millar; 2003) for the child they were working with. The students really put a lot of work into the communication passports, making valuable contributions to an assessment of the children's current skills and needs. I gave a seminar on developing communication skills using video clips from Dave Hewett's video on Intensive Interaction (Hewett; 2006) to the centre staff, UK students and approximately 15 government workers

from the homes. The seminar was generally well-received with some initial scepticism from government staff that "it is too late for the teenagers - it is not possible for them to make progress". I was able to show them video examples of an adult with complex learning disabilities making progress over time through use of intensive interaction, which I think drove the point home that anyone at any age with any level of ability can develop their interaction and communication skills with the right input. Many of the carers were really crying out for help and guidance as they had had no training on these issues and genuinely didn't know what to do. Following this, I was able to spend one morning videoing the students working with the children and coaching them in the use of Intensive Interaction. The centre staff needed more hands-on demonstration as I was not able to coach them verbally! However, I have to say that language was not a barrier to interacting with the children - the fact that communication goes beyond language was apparent to all. Both the staff and students picked up the principles of Intensive Interaction well ((Nind & Hewett; 2001) - these not being entirely new to staff due to Dr Suzanne Zeedyk and Dr Cliff Davies' previous visit) and were very motivated and hard-working, just loving to see the progress that the children were making day-by-day. Afternoons were spent taking the children out to the park for further play and interaction, which just would not have been possible if the students had not been on placement.

On my last day, I visited an orphanage for 'the deficient' (111 children aged 8-21) in Bals, a neighbouring town much smaller than Slatina. We had to apply to the government for official passes permitting us to visit. As we entered the orphanage grounds, children started waving and running up to greet us - we created so much excitement - I realised immediately that visitors were a big novelty here. The Director claimed that he knew nothing of our visit and initially seemed a bit suspicious and defensive. We were ushered straight into his room where Alex had to show him the official documents and do a lot of explaining. We were stalled in his room for quite some time, with two vivacious teenagers with learning disabilities popping in and out and acting proudly as our hosts, fixing us drinks. The director explained that he was very open to specialist help and would like for a centre like Casa Lumini to be set up at Bals so that the children from the orphanage could attend. By the time we came out of his office, most of the children had been sent outside. We were first shown a very nicely decorated 'leisure room' of which the director was obviously proud. He said that they had been able to renovate this room thanks to a large donation from a wealthy Romanian family, but he did not have enough funding to make all the rooms look like this. Most bedrooms slept about 6 and were very impersonal. We were only shown around the ground floor. Outside, we were 'mobbed' by lovely excited children who were lively and fun. They all wanted to be hugged, to hold hands, to greet us with a kiss. Staff were miming to us not to get too close because they had nits, but how could you withhold human kindness from these children who were so desperate for love and affection? There were 8 staff on shift, which meant that they couldn't even properly supervise or care for the children (they were sadly dirty and smelly) let alone interact with them. These kids' worlds existed only within the 4 walls of the orphanage. The majority of them either sat doing nothing (there were absolutely no activities laid on) or wandered about doing as they pleased, with plenty of health and safety risks. One girl had made herself an absolute modern art creation from scraps of rubbish that she had found in the grounds; she carried it everywhere with her like a treasured possession. More able children were able to attend 'school' which was in the grounds of the orphanage. It was very old fashioned, rows of lift-up desks and a board at the front of class, not the ideal learning environment for most kids with learning difficulties. The children were streamed by mental age, so you could be 21 years old and have been in the '8 year old class' with younger children

ever since you arrived at the orphanage. Some of the children presented as having only very mild to moderate learning disabilities, I wasn't sure how some of them had come to be in the orphanage for the 'deficients' at all. Alex explained to me that all it takes is for a child to fall behind in school or show 'emotional' difficulties; some of these children turn into a self-fulfilling prophecy. One child attending Alex's centre had been sent to Bals, having previously lived with a loving foster family for 3 years. The government had stopped funding the foster family and it was with deep regret that they were financially simply unable to keep her. She regressed terribly during her time at Bals and has never talked since.

I would like to wholeheartedly thank Alex and Sandu for their hospitality. Their home is warm, welcoming, relaxed, fun and friendly. It has a real family feel, with members of the extended family and friends always visiting and helping out; Sandu's Mum was kind enough to cook for us all every day!

In 2007, Sandu and Alex plan to open a Respite Care Home in the village of Plopeii in the countryside, which will be able to offer short breaks and holidays for the children in a safe and loving environment with plenty of opportunities for new experiences and therapies. It will also be used as a transition home for children who are ready to be fostered so that they can get used to family life. One of the major aims of the charity is to find loving families who would be willing to foster or adopt the children who live in the Government group homes. If these children do not get fostered or adopted, they will go into an institution for 'adult deficient', which is an unbearable thought for their future, particularly when the staff at the centre have worked so hard opening up their worlds through interaction and communication.

What Alex and Sandu have managed to achieve has only been possible with the support and fund-raising of the Orphans' Family Project (a division of Lighthouse International Ministries) and students from The Medlink Romania appeal. I am so grateful to have been given the opportunity to see their work first-hand and support them in some small way. It has certainly given me a whole new perspective on my work for the NHS here in this country.

Senior Specialist Speech and Language Therapist for children with ASD/ complex needs (Sefton PCT and Sefton Joint Services Intensive Interaction Coordinators Team) and Clinical Tutor (The University of Manchester).

