

RSA Design & Society. *Design and Rehabilitation*. Transcript of an expert seminar on a design-training pilot for people with spinal cord injuries held on Friday 28 May 2010 at the Royal Society for the encouragement of Arts, Manufactures & Commerce, 8 John Adam Street, London WC2. *With* Danny Brown, Paul Kennedy, Emma Linley, Stef Cormack *and twenty further participants from clinical rehabilitation, design and the disability charities; chaired by* Emily Campbell.

Background and speakers



fig.1

The RSA Projects team is embarking on a new design-training pilot for people with spinal cord injuries. We aim to test the idea that design as a discipline, or structured thought-process, can address the dramatic loss of confidence and diminished motivation that can result from a sudden physical impairment, and contribute to independence. Working with this group on a new model of design-training focused on self-reliance and creative resourcefulness will yield knowledge with potential for widespread replication among other groups of people whose independence, fulfilment and social participation are challenged.

A small, expert seminar was organised for 25 participants at the RSA in order to give exposure and scrutiny to the proposal from several perspectives. Speakers and guests included clinical specialists in rehabilitation from six of the eleven UK/Eire specialist spinal cord injury centres, designers, representatives of the main spinal injury charities and other experts in design and/or disability.

The keynote presentation, *Rehabilitation from a Designer's Perspective*, was given by **Danny Brown**, an internationally celebrated digital designer who spent much of 2003 and 2004 in rehabilitation for spinal cord injury at Stoke Mandeville National Spinal Injuries Centre. Three short, responses to his keynote, and to the RSA's proposal, were given by **Dr Paul Kennedy**, Head Psychologist at Stoke Mandeville, **Emma Linley**, Head of Occupational Therapy at Stanmore National Spinal Injuries Centre and **Stef Cormack**, Services Manager from the Back Up Trust. This is a transcript of the presentations and the roundtable discussion that followed.

The RSA believes that while designers are professionally charged with deploying qualities of resourcefulness and self-reliance, these characteristics would be more widely distributed if more people learned design. — Emily Campbell

Presentations

Emily Campbell, the RSA's Director of Design, introduced Design & Rehabilitation as an innovative compound; both the subject of the seminar and the title of a new project proposed by the RSA.

She said that the Royal Society for the encouragement of Arts, Manufactures & Commerce has a time-honoured relationship with design, but that last year it had published a new account, arguing that design's potential today was to make people and communities more resourceful and self-reliant. She explained that designers are very resourceful – practical, good at improvising solutions, comfortable with uncertainty and brave about sorting out complexity and disorder. She illustrated this practical resourcefulness with a recent example: Min Kyu Choi's folding 3-point plug (fig.1). Choi is a graduate of the Royal College of Art; a professional designer in training. However, Campbell also invoked an image of a door propped open with a cork from the international design consultancy IDEO's project *Thoughtless Acts* (fig.2), a collection of 'intuitive' acts of design by non-professional people. The RSA believes that while designers are professionally charged with deploying qualities of resourcefulness and self-reliance, these characteristics would be more widely distributed if more people learned design.

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no. 212424 and in Scotland no. SC037784

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Designed by John Morgan studio



fig.2

The RSA needed to prove that its hypothesis was true – design makes people more resourceful and self-reliant – and to find a testing ground for it. Campbell chose spinal cord injury as a focus for the project for two reasons: firstly because it is possible to argue that spinal cord-injured people have experienced a sudden and dramatic loss of resources; and furthermore, the point of rehabilitation is to regain self-reliance or independence.

Campbell explained that the outline proposal has been widely circulated among clinical specialists in rehabilitation, the spinal injury charities, designers, disabled designers and other spinal cord-injured people and that for the most part it had aroused keen interest. The purpose of the expert seminar was to give scrutiny to the concept from all these perspectives at once; in order to help define it and answer some fundamental questions, for example:

- *Should the pilot centre on occupational therapy for inpatients, or outreach services for people living with spinal cord injury, or both?*
- *What do we mean by design training? Design appreciation or full scale vocational training? Both? Something in between?*
- *How should design be explained in this context, and is it the right word?*

Campbell mentioned that an RSA colleague recently asked if design could be construed as a compensatory skill; a kind of “intellectual prosthetic”. She recognized that while some participants around the table would definitely say yes, for others new to design, that notion would take some explaining.

Danny Brown introduced himself as a designer and an artist working in digital animation, noting that he was also a designer and an artist before his injury in 2003. He explained that he is not a disability expert and that he would simply present his personal experience as a person with a disability.

Brown was born in Toxteth in the 1970s, with a minor spinal defect, in fact, although unrelated to his later injury. Bullied at school, he became very insular and got into computers. In the 1980s when an Apple Mac cost about a thousand pounds, he was introduced by a family friend to Roy Stringer, who owned Liverpool’s only Apple dealership. Stringer invited him to use the computers in the evenings and by this means he acquired an informal training in design. By the late 1980s, Roy was running Liverpool John Moores University’s Learning Methods Unit, who ‘adopted’ Danny Brown as kind of a mascot for the department. At the time they were working on the HeadStart system, which allowed someone to control a mouse by using their head – although at thirteen, Brown was too young to be involved in the project. But when he went on to work in digital and interactive media much of his work, ironically, was on medical projects. His focus is now on applied arts.

Brown was injured at level C4-6 swimming in the sea in Barcelona in 2003. He spent ten months in hospital; four months of acute care and five in rehabilitation. He got pneumonia and technically died a couple of times in St Thomas’s Hospital in London, before being admitted to Stoke Mandeville. He can now use his arms but not his fingers.

Brown described how classes at the National Spinal Injuries Centre reflected things he knew from design. The therapists would work with you on a specific task or goal that you wanted to achieve – it was something like a design brief. One day, for example, he wanted to start playing his Playstation again, so they adapted the console so he could.



fig.3



fig.4



fig.5

Now that he lives in an adapted flat, the occupational therapy he gets is delivered as a community rather than a personalized service like the one you receive as an inpatient. Occupational therapists (OTs) have a catalogue of off-the-shelf devices that can be supplied. But as a designer Brown knew from the start he could just get on and design something for his own specific needs.

When you say “design”, most people probably think of Laurence Llewelyn-Bowen, but interior decoration is only one facet of design. A more interesting definition of design is the management of constraints. A chair has to hold a person; that’s not negotiable. There may be a fixed budget for its production. But there are also negotiable constraints, like colour. This area of negotiable constraints gives quite a lot of scope for people like Danny Brown to improve their situation.

Design is this ability to change the things that happen to you every day.

— Danny Brown



fig.6

Brown said that while disability was a negative way of looking at a challenge, design is positive. He gave the example of the iPhone. In principle it should have been an amazing device for him – enabling him to dial without using finger splints or an adaptor. But he can’t operate the big central button that needs applied pressure. He stuck on to it a rubber half-sphere you can buy in any hardware store to stop doors banging, and now it works (fig.3). Design is this ability to change the things that happen to you every day.

Although the traditional typing splint supplied to people with impaired mobility works (fig.4), the focus of where you are typing – the end of the rod – is not where you would be used to focusing before your injury. Brown found this awkward when he started rehabilitation. He’d used to use his computer with both a keyboard and a trackpad, but trackpads require physical touch by skin so they don’t work with splints. He designed a typing splint with finger touch for a track pad (fig.5 & 6). When he told the OTs at Stoke that that he didn’t like their splint they thought he was “a bit mad”, but once he’d worked with them to design it, they wanted to give his device to everyone. It’s a simple piece of Orthoplast, which you heat it up and it becomes pliable so you can mould it around the body parts. When it’s time to make a new one, you can mold new Orthoplast around the original. It was important to make it easy to repair. He and the OTs used the *Keep It Simple Stupid* principle, borrowed from the US Army – whatever they build has to be fixable with the contents of a standard issue box. This is a nice way of approaching a problem.



fig.7

Brown gave some examples of user-centred design – the name, he explained, for a design process rather than designed objects.

He has lots of care assistants coming in and when there’s a new one they get a lot of instructions for how to use his individual devices. Care assistants come with their own notes as well and so there’s a mountain of documentation. He puts all of this into a step-by-step booklet; very easy to follow and very much like a recipe book. This single source eliminates confusion and the overwhelming amount of information you get in a new job.

All accessories for disabled people seem to be beige or black. The standard supply gloves, for example, are very motorbike-y, which didn’t suit Brown’s ‘dandy style’, so he and his mother designed a very simple pair in different colours (fig.7). He pointed out that altering something off the shelf it is cheaper and faster than ordering disabled kit.



fig.8

As a designer and artist, Brown eventually needed a splint for drawing. Living in the community, you can’t have a care assistant who’s there all the time, so he needed a splint he could put on by himself.



fig.9

That got him thinking about a splint and pen in one, and he improvised with Blu-tac and a pen (fig.8). The result was a bit flimsy for drawing but you can write with it. Next he showed a pendant alarm which he declared to be “the most awful piece of design”. Amongst other demerits, it has an indented red button that he can’t actually press on his own. He sent it back to the supplier and it came back the next day with an add-on clear shell. This provided some leverage so he could press that button, but was still a terrible piece of design – the shell easily fell out. Then he realized that the shell looked like a computer mouse, and that with it he could create a way of drawing without even lifting the pen. He taped the pen on to the “mouse” and it worked very well, so he got out some orthoplast and refined the device (fig.9 & 10).

The more designers there are in the field of disability able to communicate with one another, the more exponential will be the effect. — Danny Brown



fig.10

Danny described himself as very disabled, but still able to hold down a career. He explained that he uses design in part to retain a personality amongst all the beige and black equipment that enables him to keep his independence. The more designers there are in the field of disability able to communicate with one another, the more exponential will be the effect. Design will enable disabled people to increase their independence. Suffering inevitable depression and day to day problems, Brown said it helps to think ‘in the future’; to face down these problems and try and overcome them one by one and bit by bit like a designer.

Emily Campbell recalled Danny Brown saying that because a lot of what you do in rehabilitation is like design, formalising it as ‘design’ or design-training is a good idea. She also remarked that, because design really grew and became a profession in the 20th Century, it is principally associated with mass production of ‘universal’ solutions. But design can do the opposite; it is the ultimate personalization tool, and Brown is an exemplary protagonist; regularly ‘disrupting the catalogue.’

Discussion

These presentations provoked a discussion centred on three issues: the practical challenges of introducing design training for spinal cord injured people; the semantic problems associated with the word ‘design’; and the imperative of communicating the idea of design vividly to people who may not have considered design before.

The Practical Challenges

A consultant commented that often patients can see the problem and the solution but have no way of bringing the solution about. They need to know what to do if they have an idea, even if they’re not necessarily considering design as a career pathway. Professional designers could help with this progression of ideas – one of the potential benefits of this programme is a network of experts and amateurs who know about design, but also how to produce things.

Although product warranties can be problematic, there’s a lot of common sense in changing things you already have. This is a great way of introducing people to the idea of design, and showing them how much design they probably already do, even though

Paul Kennedy introduced himself as drawing on 25 years of experience in dealing with people with a spinal cord injury, and began with two main points. Firstly, that although people think that spinal cord injury is very specialized, he is professionally concerned with how people deal with adversity and changes – and this is the story of the human race. Secondly, that we all have to recognise our own mortality and our capacity to function in an environment that we do not create. Most of us, if we live that long, we will be spending at least 11 years of our lives with a disability.

In rehabilitation you take people from total dependency to them being independent. This process incorporates a clash of models from acute medical care to vocational re-education. It’s important to acknowledge what people need when they suddenly enter this intense new world. Patients want individualised patient care and active involvement as team players in planning and decision making. They want clear, accurate and truthful information. They need the involvement of family and friends to lessen the disjunction between their previous identity and the life and real world beyond rehabilitation. They need assistance with new skills and empowerment; input from peers with experience of injury and rehabilitation; and help to address psychological issues like body image, vulnerability, loss of identity and control. In rehabilitation it is important to remember that hospitals are a clinical environment and in most respects not like the world outside; this can compound issues of exclusion.

Kennedy quoted a formula for successful psychological coping with spinal cord injury. Success is “the person with the injury sustaining an

they might say they could never be a designer. The next stage is to ask “who can help me with this? Where do I get it made?” Although professional designers themselves wrestle with this very problem, they have plenty of production experience to impart.

A spinal cord-injured designer said his splints from rehabilitation twenty years ago at Stanmore are covered in glue. To send them back would cost £25 and the NHS won't fund it so he just moulds them with more superglue. An improvisation like this is a useful example. There's little point showing someone a technically virtuosic building by Zaha Hadid or a jaw-dropping fashion show by Alexander McQueen and expecting them to find the designer in themselves. You have to show them solutions to problems such as they might conceivably have come up with on their own. The folding plug, even though it shows a trained designer's judgement of form and materials, is still a good example. We can all imagine how useful it would be if you could just collapse a big fat three-point plug into a flat thing. It corresponds with common sense.

An occupational therapist said that little things are surprisingly important. One patient was unable to type after bamboo chopsticks went into decline – she can manipulate bamboo but not plastic. She advises patients “if you find cutlery in a restaurant that works, ask them if you can take it home.” She also pointed out that you can buy Orthoplast, and OTs will usually give patients some to take home and do things with it. Danny Brown confessed to just helping himself on hospital visits!

Only in James Bond films do you find people who have something physically wrong with them taking over the world. — Paul Kennedy

It's important to consider timing. People in hospital are a mixed bag of characters getting their head around a lot of new things. Back-Up have a lot of success because they engage people after they've been discharged from hospital; at a secondary stage in their rehabilitation. After all, the day you really start rehabilitation is the day you get pushed out of the doors of the hospital.

Still, the idea of introducing patients to design in hospital is a good one. Some might need encouragement to join in, and being inclusive is absolutely crucial. That's the key consideration and it's hard to generalize. Although a 21-year old might be better able to adapt and change their ways, there's no reason why a 70 year old spinal cord-injured person should take less interest in what design can do for him.

integrated view of the self while constructing a new reality that is both hopeful and credible”. In summary, he said, patients need a helpful future orientation in practical terms, and an optimistic vision for a future life with their injury.

It is a fact that 75–80% of people with spinal cord injury go back to living a life that is commensurate with their original goals. Most are not depressed. A student looking at the history of government support of people with spinal cord injury in the 1940s found that 80% of patients are back to work within a year (the figure today is 35%) Even in the early years of Stoke Mandeville in the 1940s, 90% of patients were discharged to live at home.

The factors that we know do *not* make a difference to a patient's psychological adjustment are education, cause of the injury, social class, level of injury or intelligence. The list of factors that *do* make a difference is much longer and more complex: positive reframing, who caused the injury, not venting emotions, acceptance, low wishful thinking, quality social support, internal attributions, attainable goals, history of emotional distress, purpose in life, engagement in the world around, sense of humour, completeness, opportunities for personal growth, ability to make sense, habits of avoidance or denial, self-belief and low use of drugs and alcohol.

There is some evidence that people with slight or minor spinal cord injuries have more difficulty coping than those with more serious injuries. A lot of resources are currently put into finding a cure for spinal cord injury. Yet when you consider how more than 80% people with spinal cord injury are making a successful contribution to society and economic life, Kennedy feels strongly that as much effort should be put into improving their quality of life as into eliminating their disease.

Kennedy made the fundamental point that if you are ‘sorted’ psychologically in the period of rehabilitation then your functionality will be better. Some patients describe having opportunities for growth despite the losses, and describe their fundamental goals, values and sense of purpose in life as unchanged or even enhanced.

However, the attitudes of able-bodied people towards disabled people can often damage their psychological confidence. Able-bodied people, for example, tend to make assumptions about the disabled person's functional limitations, to react with aesthetic sexual aversion, to interact uncomfortably with disabled people and to attribute negative character qualities to them. “Only in James Bond films do you find people who have something physically wrong with them taking over the world.” There's also a pervasive idea that a disability is evidence of one of your forbears' evil. Able-bodied people's fears and reactions range from loss of empathy to fear of contagion, burden or ostracism, through exaggerated sympathy, patronising benevolence and guilt. Rarely are able-bodied people able to feel full empathy and equal status with a disabled person.

Emily Campbell remarked that although the discourse of design for disability has tended to focus on the ergonomic qualities of products and environments, we should remember that design but can also address the psychological – Danny Brown's point about the importance of fashion to self-esteem is an example. Meanwhile the special skills of communication and graphic design have great potential to address image and the attitudes of able-bodied people.

The Semantic Problem of Design

Emily Campbell reported that some people consulted on the proposal felt that it should be framed as 'life skills' rather than design. Although there was support for formalizing the problem-solving approaches of occupational therapy as design, the word design puts a lot of people off. When a summary of the project was put up for feedback on the online messageboard of the Spinal Injuries Association, it got a pretty rough reception, above all from spinal cord injured members who found the terms 'design' and 'design training' confusing and alienating. Although the proposal has had a warm reception from professionals, like those attending the seminar, the people whom it's supposed to benefit are harder to win over. Is design the right word?

While the OTs certainly learn from previous experience, each patient has their own unique injury and presentation, and their own priorities:

— *Emma Linley*

Design is perceived as a bit lofty. Although in some ways we all use elements of the design process all the time, it's a remote concept. People misinterpreted the session on design that was advertised at Stanmore and were really not sure about it. Only nine people signed up. The flyer explained design quite simply as "deciding what something's going to be like and how it's going to work", but even that was hard for people to get. But actually patients have to get around all sorts of jargon – we should keep the term design.

An MS patient told how she became passionate about the stigma around disability and frustrated with the equipment she was given. Through her health changing she started to look at design and now runs a website promoting good design. She identifies the problem as people's tendency to associate design with high-end objects. In fact, OTs ways of working are much closer to what we mean: they introduce a set of problem-solving skills rather a set of designed products.

Emily Campbell asked if the room thought designers are born or made? The proposal depended on a belief that you can be made to think more like a designer, but in reality, how would you go about teaching a useful amount of design in a few days?

The designers in the room replied that adaptation and hacking are what we have done for the last 1,000 years. Putting these habits on a pedestal as 'design' or 'a design' is not helpful. You need to get people to be brave enough to make their own rules, and to have a

Emma Linley began by saying that occupational therapy (OT) is a relatively little-known profession to the general public, and by explaining that it operates within a range of hospital and community settings, dealing with physical, psychological and social issues. For simplicity she broadly defined OT as "the use of purposeful activity to promote independence". Within this remit the objectives of OT at the London Spinal Cord Injury Centre (LSCIC) are to optimise each patient's physical and verbal independence, to allow them to return to their community, within an appropriate time frame, with the ability to maintain their health and independence.

Guided by the philosophy of purposeful activity to engage patients she went on to outline that the OT service provides therapeutic intervention to promote and optimise recovery and implements compensatory strategies to replace lost function.

OT intervention at the LSCIC begins on the day of admission where the patient finds themselves lying flat in bed awaiting surgery, utterly dependent for all their needs. Alongside physical therapeutic interventions, the provision of equipment such as prism glasses and environmental control units can already begin to offer patients the opportunity to engage with their environment and have some independence.

Once surgically stable, the OTs mobilise the patients into a wheelchair and explore their functional potential within the limits of their injury. For some this may mean trialling electronic assistive devices such as power wheelchairs driven by chin control and accessing a computer via a mouth switch; while others may look at how they can move themselves from their bed to their wheelchair, wash and dress themselves and return to driving.

Throughout the patients' initial rehabilitation (and during their lifelong follow-up) OTs need to be creative in finding solutions to their patients' problems. While the OTs certainly learn from previous experience, each patient has their own unique injury and presentation, and their own priorities: this requires the patients and OTs to work together to generate solutions.

In response to the RSA's Design & Rehabilitation outline proposal, Linley highlighted the parallels between the theory of design and occupational therapy practice. In essence, both are creative, adaptive and problem solving; the marriage seems to be a logical one.

Linley gave a detailed response to the RSA's proposed training programme of short introductory presentations in the spinal cord injury centres, and longer residential workshops. She felt the former would be hard to fit into the current comprehensive service delivery but speculated that a one-hour design 'taster' session could be accommodated into the already established patient education programme. Ultimately this could be delivered by the OTs to ensure sustainability, as professional designers or design tutors might find it difficult to maintain their commitment.

Linley also felt that a spinal cord injury centre based, designer-led, two-day session for both in- and outpatients who had expressed a particular interest could also be accommodated, if current service provision were temporarily suspended. She gave the Spinal Injury Association's 'Your Voice' training for patients on knowing their rights as a successful parallel example.

The proposed residential workshop was thought to be an excellent opportunity for individuals to explore design practically and Linley recommended that no age or injury-level thresholds should be put around this opportunity.

designer's sense that problems have solutions. Danny Brown has this belief: a sense of agency that you can solve a problem. We want people to 'have a go' – like the chopsticks example and the superglue-d splints and Danny Brown's gloves. This is just what normal people do to get by. If you ask everyone to choose a favourite object, it might be something straightforward or it might be an improvisation – using something for a purpose it's not intended for. Everyone does this, and in that sense everyone's born a designer. We all have the ability to tie something down with a bit of a string or prop open a door with a chair. Back-Up added that they would not expect people to leave with design skills, but with enhanced skills for everyday life.

A consultant recommended that there should be formal training in design for OTs; training in lateral thinking processes. He also recommended that the RSA's residential workshop, if it were rolled-out successfully, should focus strongly on attracting individuals who might take on design as a professional vocation.

A product designer who lost his language as a result of a stroke, pointed out that his problems were not physical, but psychological; associated with writing and communicating rather than mobility. It took him three years to re-learn how to use a computer, but he's now writing a book. He discovered that A5 paper formats help him because they restrict the amount of information on view, and describes A5 as his 'wheelchair'. He has no doubt that the designer in him helped him to get to this position; it was the designer in him that could look at the whole environment of interrelated issues.

The Communication Imperative

Another designer said that Danny Brown and David Constantine's (David Constantine is a spinal cord-injured designer and founder of the disability charity Motivation) powerful stories need to be brought to people to help them understand design. As a result of the amazing things Danny Brown said in his presentation, people around the room were already thinking about what they could do. It's imperative to share that knowledge and best practice. A good amount of accrued information will allow this project to move forward. She also questioned whether we need training – why can't we just aim to build awareness. Training sounds like work; this programme should emphasise what design can do for *you*.

Another participant reinforced the communication imperative. Having heard three design initiatives in the last 15 minutes that he'd never heard about, he'd become convinced of the need for people to know this work exists. The key is to let people know that design is out there and that they can participate in it. In conclusion Danny Brown commented on a palpable sense of something starting with the people in the room – a new link between design and rehabilitation. He reiterated that design has enabled him to be a confident disabled person; we just need to harness it.

The final two practical aspects of the RSA proposal, scholarships for vocational university training in design and internships for disabled people in design businesses, were welcomed by Linley with the caveats that scholarships would need to be fully-funded and supported with accessible environments and any care requirements, and that work placements should be for a minimum of six months so people can acquire real benefit.

Finally Linley made the point that having a disability does not mean that you should only work in design for disability. Emily Campbell clarified that one intended outcome of the pilot was an increased number of disabled people entering the design profession, but not necessarily becoming specialists in design for disability. Danny Brown is an example of a disabled designer whose work serves a wide general public and arts constituency with no connection to disability as such.

Stef Cormack introduced her organisation, The Back-Up Trust, as aiming to enable people with spinal cord injury to realise their full potential. They do this by inspiring people to transform their lives, challenge perceptions of disability, and building confidence and independence and offering a supportive network. She declared a feeling of real affinity with the RSA's pilot project; because challenging experiences like it can transform people's lives.

Cormack used Back-Up's mentoring scheme as an illustration of an existing programme that succeeds in transforming lives. Mentoring by spinal cord-injured peers increases the number of positive coping strategies being used by the person being mentored (these strategies are linked to positive adjustment to injury and better outcomes in life) – and helps the mentors too. For example, Robert, 38 years old and living with his partner, injured his spinal cord when he came off his motorbike in 2007. It took him a long time to come to terms with his injuries, and he stopped being around the bikers who had been so important to him before his injury. His mentor was a biker too and Robert was able to reciprocate with advice on engineering. This made Robert realise he still had a lot to offer and he's going on to more training in design to develop his career.

That's just one story. Back-Up, in partnership with specialist activity providers, run rehabilitative courses in drama, going back to work, getting around cities, and outdoor/sporting activities – generally enabling people to climb their own personal mountain. The courses are led by volunteers with and without spinal cord injury from all walks of life and this has great value: volunteering brings something unique and there is a great impact on all involved.

Back-Up warmly welcomes the RSA's pilot scheme and will take a great interest in how it progresses.