



MAKING FREEDOM REAL: EXPLORING THE USE OF MAKATON BY ADULTS

A Discussion Paper from the Centre for Welfare Reform

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FEBRUARY 2016



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Contents

SUMMARY	3
1. INTRODUCTION	4
2. MAKATON FOR ADULTS	6
3. MAKATON TODAY	10
4. TIME FOR CHANGE	15
5. CONCLUSION	19
BIBLIOGRAPHY	20
ABOUT THE AUTHORS	21
PUBLISHING INFORMATION	21
THE CENTRE FOR WELFARE REFORM	22

SUMMARY

The purpose of this paper is to investigate the reduction in the use of Makaton as young people move from primary to secondary schooling and on to adult life. It arose out of a conversation with staff at Makaton headquarters about priorities within the organisation, at a time of reduced funding, for the spread of training in the use of Makaton.

It seemed likely to the authors that Makaton use does ‘peter out’ as people get older but this seems to lead to reduced opportunities in later life for communication.

Some people with communication difficulties who are unable to communicate their wishes, preferences and dreams to anybody use Makaton. There are also good examples of the use of Makaton with adults. So we explore why the use of Makaton reduces and suggest how this problem might be reversed.

With the arrival of the 2014 Care Act (which came into effect in April 2015) and its emphasis on the client being at the centre of the planning process, the issue of good communication has become even more important.

I. INTRODUCTION

Makaton is a language programme that uses signs and symbols with people who are described as having communication difficulties.

Makaton was designed and used in the 1970s in a hospital for people who had cerebral palsy and hearing impairments. Makaton was designed with the hope that it would encourage interaction with peers but also integration with the local community.

Since the 1980s it has been introduced to special schools and has since focused on this as the main area. Makaton, however, have recently included symbols on their website as a free download for work with adults but to use them or to know how to use them, you have to access their training. Figure 1 gives an example of what Makaton symbols look like.

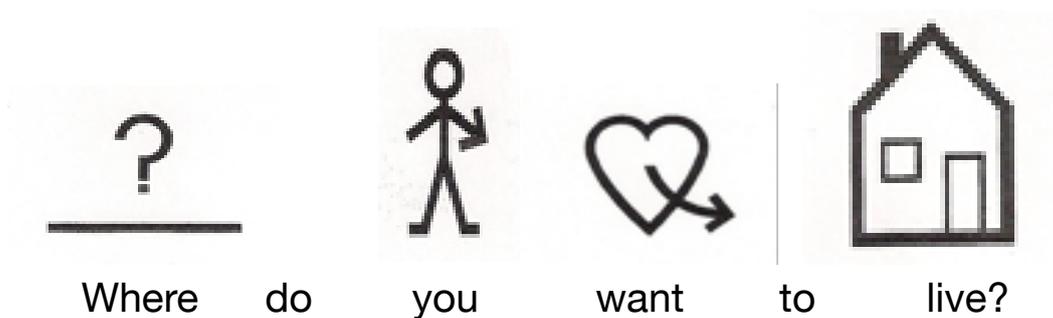


FIGURE 1. Makaton Symbols

Evidence

The information in this paper mostly comes from two organisations in our geographical area. Names of people and organisations have been changed to ensure confidentiality. One of the authors worked as a care worker for several months in an organisation providing support to adults living, supposedly, in their local community. Conversations have also taken place with a number of people also working with adults described as having a learning disability.

Staff working within the supported living setting used as our main example mostly felt that Makaton was not needed. One member of staff feared that a client's vocal cords 'would seize up' as signing might replace the need for

speech. Other staff felt that clients had grown out of Makaton use. One client in his 20s was described as unable to talk or sign because of old age. Most of the clients were aged 20 years or older. A minority of staff were keen to learn Makaton and felt it would be of great benefit to the people that they support.

The organisation's in-house training did not place emphasis on good communication stating: "You, as support workers, know the clients better than anyone and even in some instances better than their families or the clients themselves."

2. MAKATON FOR ADULTS

Mel's experience

Two young adults were living in the first property where one of the authors, Mel, spent 6 weeks.

Terri was described as having mild cerebral palsy and autism. Staff advised that she could not read and also required other forms of support. Terri spends three days a week going to a day centre and likes buses and transport.

Harry had more complex cerebral palsy. He used to use Makaton and did communicate but now support staff said he had 'grown out of' Makaton and had little speech. Harry loves trains and lifts according to staff and still does use some natural gestures that staff have come to recognise. Harry quickly recognised the basic signing, when Mel used some Makaton and he began immediately to respond.

As this was an induction to an organisation Mel was given permission to do some cookery with Terri using verbal prompts to see how much support was needed and only giving sufficient support to increase independence. Following this she adapted a recipe using Makaton symbols and spent 15 minutes as they went through the recipe. The result was very encouraging and Terri went from believing she couldn't read to being able to and cooking with some support. As for Harry, Mel used a limited amount of Makaton, although other staff expressed some disapproval about signing. The interaction drew a positive response from the client and always got a response.

In the bungalow next door was a man, Tom, who staff said had alcohol-induced dementia and could get confused. A male support worker liked the idea of Mel using symbols with him so that it made having a shave not such a shock. Unfortunately this did not happen, as other staff were against this idea. Staff said that their own strategies had not worked and were dubious about Mel's suggestions. Mel recommended that they check out research already conducted by Makaton, but staff did not seem open to this idea.

The second property was linked to the same organisation and housed two women. One had a mild learning disability and was very able and was able to read and write with little support. The other woman, Sharon, has been diagnosed with autism. Sharon was enthusiastic and wanted to try everything that was presented to her. Sharon knew Makaton – she was self-taught by watching Mr Tumble. She enjoyed signing at the table. Sharon was fluent in saying hello and "I am Sharon" and was very keen to learn more.

Sharon's speech was good and Mel felt she did not really need any help with communication. She just enjoyed using Makaton. The other woman was not so keen.

"Makaton is not needed here," Mel was told by a support worker, "but Sharon does like Mr Tumble." "Are you like the lady at the bottom of the screen who does the signing on TV?" Mel replied that she was not.

The third property was linked to the same organisation. This home was for eight women all with a variety of needs. The ones that Mel mostly had dealings with had mental health issues, cerebral palsy and learning difficulties, dementia (which Mel later learned was likely to be in its later stages), and another woman with learning difficulties. Mel was not allowed to use Makaton here. "It will cause Diane's vocal chords to seize up!" was the opinion of one member of staff. Mel tried to explain that Makaton's purpose was to aid spoken communication - not to cause unused vocal chords to seize up. Nevertheless she was told "We don't want it!". Mel used the fact that she had been using it with her son for 18 years, excusing any Makaton use as a matter of habit: "Sometimes I do it without thinking!". The staff manager laughed it off and said it was acceptable in those circumstances. Mel gave her iPhone to Diane, the lady with the most Makaton knowledge, and told staff she was playing 'a game'. In fact it was the *MyChoice* app. She was told "I hope you don't get beyond level four!" (there is no such level). Diane embraced it and it seemed to bring back memories. At the end of the shift Diane was reluctant to hand back Mel's phone.

Use of MyChoicePad

Current resources that are now available include the *MyChoicePad*, designed for iPad. This is an educational app that uses Makaton symbols, signing and voice output and communication for people for people with communication or learning difficulties. A lite version can be downloaded onto an iPhone. Research had been carried out by Insane Logic about how effective this has been in aiding peoples lives who experience communication difficulties.

Insane Logic trialled the *MyChoicePad* with Choice Support and the responses from support workers were as follows (Doukas and Coulson, 2016):

- 67% saw increased initiation of communication
- 83% of staff had longer interactions
- 100% of staff found the experience satisfying or very satisfying
- 100% of staff reported the person enjoyed the experience

These results show that there is a great deal of improvement that can be made for adults described as having a communication disability. However for those that do not have access to an iPad or iPhone, what needs to change so that everyone can have the chance to say what they want?

Misconceptions about Makaton

The fourth property was linked to the same organisation. This property was for two people, both women in their early 30s. One had what was described as Williams’ syndrome and the other had Pierre Robin syndrome.

Pierre Robin syndrome features a smaller-than-normal lower jaw, possibly a tongue that falls back in the throat and some problems with breathing. This lady was very softly spoken. Again, the main member of staff told Mel that Makaton was not needed here and that “I know these girls better than anyone.” A parent added, “My daughter went to a mainstream school and therefore does not need this form of communication.”

Choices available to these women seemed to be a big problem. The staff member did treat the women as young girls. Mel was told that the lady with Pierre Robin syndrome had no concept of money or ability to decide what to wear. Makaton use by Mel (again ‘by accident’) was limited but some of stage one was introduced. While never having experienced this form of communication before, the lady could reply without struggling to get her words out. She quickly showed that she did know about money and Mel encouraged her to pay for things herself.

As for the woman with Williams’ syndrome, she was familiar with Makaton and would have secret conversations with her boyfriend in front of staff using Makaton without speech. This needless to say led to trouble. He would sign “Phone me, phone me!” She did and then staff would say that she was pestering him too much and would give her times when it was permissible to call.

The fifth property was linked to the same organisation. At a party supporting clients from the above property, Mel spoke to a young man in his late 20s (Sam). Sam has mild cerebral palsy but does have complex communication difficulties. He points to things he wants within his home environment. Mel asked Sam if he knew any Makaton. He replied that he did. Mel went on to ask if he was taught this at school. Again he said yes. Mel asked, “When did it stop?” He replied, “When I finished school.” Mel asked how did this made him feel. He replied that it made him sad. Mel asked if he would like staff to know Makaton. He said yes. The staff are

happy that Sam participates in the household chores, but this leaves Mel wondering what else he did with his day and how much choice and control over it he had.

Other evidence

A day centre which Mel visited had clients who were familiar with Makaton from school, though they did not currently use it. A man in his 40s had good verbal communication but found the symbols useful. One woman had limited speech and little signing was done with her because staff did not know Makaton, She managed to sign who her best friend was and where she wanted to live. Staff asked Mel “How did you know that?”

Mel attended a recent conference which included clients’ stories. She was listening to a man who is on the autistic spectrum who has a brother with more complex needs. While Dave, the young man at the conference, did not question the importance of good communication he did speak also about the competition between staff and the part this plays in provision for people who need support. Dave and his family felt the stress from this but did highlight that it was important to remember that it was their brother’s home.

Mel’s personal experience

Mel’s personal experience was that her son Mark did not talk until he was five years old. Mel feels that Makaton was very useful for him as it meant he could make his needs known. Mark (now twenty) still uses Makaton but only in situations where he is unable to be heard like a disco or pub, or other noisy environment.

Mel’s daughter Cheryl comments, “As a sister of a Makaton user and also someone who works within the care industry I feel if Makaton is used properly then it would be an advantage to both staff and clients.”

Going back in history to 2003, while training as a nursery nurse in the diagnostic nursery, Mel was faced with the directive that Makaton was not to be used as most of the parents were said to have their own forms of communicating with their children.

3. MAKATON TODAY

History of Makaton

Many of the first users of Makaton were adults. Makaton first began at Botley hospital, started by Margaret Walker, along with Cornforth and Johnston. In 1976 the revised Makaton vocabulary was completed. It was considered to be useful for “*various groups including: mentally handicapped [sic] deaf and non-deaf children and adults with little or no expressive speech and poor comprehension; children and adults who have mental and physical handicaps [sic] and children with autism.*” (Sheehy and Duffy, 2009)

“The research ended in Autumn 1973 – As far as Botleys Park is concerned the introduction of sign language of the deaf for deaf mentally handicapped [sic] patients has proved a great success. The patients are capable of learning it easily and using it as a complete medium for communication. So far, no limitations have been found. The group of patients is well integrated; there has been a noticeable improvement in members’ individual behaviour and reduction in problem behaviour. There is also a marked increase in sociability. Group members sign well and use signing to communicate amongst themselves. Another interesting point to note is that the group as a whole has become much more vocal and several members are attempting to imitate speech. The scheme has been very interesting and rewarding to implement and its use is recommended with similar hospital populations.”

Margaret Walker, 1977

Communication and freedom

So how important is having good communication with those around us? Surely we should be able to express not only our preferences but also how we feel, both to friends but also to professionals. When talking about good communication and Makaton to Dr Simon Duffy from the Centre for Welfare Reform he added:

“You aren’t free if no one can understand you. Freedom is a social process which involves communication and respect, allowing people to make choices which leads to citizenship. Human freedom is a natural human development.”

But the reality in some cases could be different. When asked about her experiences, Katherine, a support worker at a day centre, noted that:

“Clients move between organisations during the week. Those organisations don’t talk to each other. So standardising communication does not happen. Staff don’t know Makaton. As for person centred planning, we don’t even get invited to meetings now! Person-centred? If only that were the case!”

However she did know about the 2014 Care Act through staff briefings through Derbyshire County Council. Is this kind of thinking everywhere? We spoke to a worker in Derby City Council about his experiences:

“I have worked with people with Profound and Multiple Learning Disabilities (PMLD) who use computers or tablets to communicate. They press a symbol and the computer ‘speaks’. Many of these computer or IT based means of communication are a commonplace in school but once people ‘transition’ to ‘adults’ a lot disappear.”

Makaton and schools

So is this really the case? Does Makaton disappear during transition to adults? We paid a visit to a Nottingham College and spoke to a member of staff who said:

“How do we use Makaton? It’s as much a re-enforcement of communication. We have learners with BSL (British Sign Language). One has ASL (American Sign Language). One of the learners who uses BSL is profoundly deaf. We use Makaton because the funding for her BSL signer has run out. She’s been with us for a lot of years. She can lip read, but she understands Makaton. It’s probably better for her. She’s had to gain independence, not sitting looking at a signer.

“We use it as a re-enforcement both with verbal and non-verbal students. We start at sixteen. We’ve had people in their fifties access the college. Now, with the new education laws, we have a couple of fourteen year olds. We go from sensory to level 1 and at some point in the day they’ll all be together. So it gives them the chance to inter-act. They’re not frightened of each other. Most of the support staff have done some training.”

“I do feel that something should be done in [mainstream] schools. We are having a lot of students for whom English isn’t a first language. We use Makaton with those students who have the language barrier.”

“I agree with what Makaton are doing. I can understand what they’re doing and why they ask so much. But it is expensive! I have an iPad with MyChoicePad on. I do suggest when people say, what can I get for communication, I say get MyChoicePad.”

“I’ve had the argument with a parent of somebody with autism. Mum said “I want him to be verbal!” I said that he is verbal. I think there isn’t enough understanding with parents and carers about Makaton. They think it’s like BSL and it’s going to take over. They think: they can do that at school – I don’t need that. They don’t realise that it gives you a head start for the future.”

Makaton for adults

This leaves us wondering about the level of choice and control that people can access and how important the choices we make are to us - things that most of us take for granted even down to choosing a sandwich or drink and being part of a conversation.

“At MacIntyre we have a Communication Profile for everyone we support which helps as a guide to know how people communicate and the best way we can communicate with them. I don’t think we reinforce or use Makaton as much as we could, if I am honest.”

Head of Day Centre

We sense a strong feeling of disappointment and despair. You start school at 5 years old and learn Makaton, which enables you to talk to your teachers and peers and then when you finish school or college it stops just like that. Is that right? What about choice and control?

Play therapists on a children’s ward said that they have young people up to the age of 17. In their opinion it seemed ridiculous to stop people using Makaton when they reached a certain age. “We do get patients on the ward who use it [Makaton] but I can never remember what it is I need to do! We had a little boy in who was isolated because he couldn’t go out. We knew that he used Makaton because his mum told us. The doctor came in and said “My name is...” and the boy was looking up. So we said to him [the doctor] “Well, if you do this...!” And he understood and mum started to help the doctor to communicate with the young boy and he was no longer isolated and he was part of the conversation.”

Sharon Allen, CEO Skills for Care said:

“I’ve asked one of my colleagues in our standards and quality team to have a look at what you sent and they advise that our Common Induction Standards, developed with employers, detail what all new workers in regulated services should be signed off as competent in within the first twelve weeks of starting work. Standard 3 requires staff to communicate effectively. Workers should be meeting the communication and language needs, wishes and preferences of individuals. This will obviously include Makaton where this is the preferred language of the person being supported. You may wish to quote these standards in your work.”

Technological breakthroughs

The researchers testing MyChoicePad at Choice Support found staff highly enthusiastic (Doukas and Coulson, 2016):

“It’s the best thing that’s happened to T since I started working with him.”

“It’s great seeing how excited he is using it – it’s fantastic; and ‘he’s fully involved with his own choices.”

This shows that Makaton is being used successfully with adults to improve their communication and quality of life! But in a time of budget cuts, what if you’re unable to purchase an iPad? What happens then? Many of our clients do not even have a mobile phone or have control of their own money. This leaves us wondering about the slogan, in use in disability activism since the 1990s:

“Nothing about us without us.”

If you have a communication problem how can you make your choices and needs known?

A speech and language therapist we contacted described as very “old fashioned” any idea that Makaton was somehow for children. But she described how one headteacher she encountered a few years ago said that Makaton in that school should stop being used when the child became sixteen. The therapist agreed that an iPad and suchlike can be expensive and said that, in the absence of expensive technology, speech and language therapists would generally revert to old fashioned print.

There followed a conversation with a college lecturer who advised us that as a disabilities lecturer involved with students with a learning disability she used Makaton – it was even presented as part of the staff’s ‘continuing professional development’:

“It proved to be very effective although some students used a mix of Makaton and BSL, which I found confusing. And, because Makaton is world recognised with few variations it was helpful for communication with our international students.”

If it is available at college why not within a clients home and with support staff? And what would be the impact be for the client who once learned Makaton at school and no longer has access to it?

4. TIME FOR CHANGE

Transforming care

Transforming care: A national response to Winterbourne View hospital identified outcomes which should be achieved for people with a learning disability and/or autism:

- Being safe
- Being treated with compassion, dignity and respect.
- Being involved in decisions about their care.
- Knowing those around them and looking after them are well supported.
- Making choices in their daily life.
- Receiving good quality general health care.

But is this taking place and is it presented in a way that clients or customers can understand?

“As an individual and family services professional... Makaton is an added tool which clearly helps communication with many. The important thing is recognising that everyone can communicate in some way and it is everyone’s responsibility to ensure that communication is recognised, understood and developed, thus placing the individual at the centre of their support planning of their life.”

Anon

Royal College Standards

The Royal College of Speech & Language Therapists recommends five good communication standards (2013). Good communication underpins all these outcomes. Most people with learning disabilities have some speech, language and communication difficulties. These can be hidden or overlooked.

Standard 1. There is a detailed description of how best to communicate with individuals.

Standard 2. Services demonstrate how they support individuals with communication needs to be involved with decisions about their care and their services.

Standard 3. Staff value and use competently the best approaches to communication with each individual they support.

Standard 4. Services create opportunities, relationships and environments that make individuals want to communicate.

Standard 5. Individuals are supported to understand and express their needs in relation to their health and wellbeing.

A care provider felt:

“Working with individuals whose lives are affected by autism for over 20 years I have used and still use, even if I’m a bit rusty, Makaton. Finding appropriate methods of communicating with those entrusted to our support should be as important as breathing.”

Whilst being able to express your needs and where you want to be, not being able to do so can have an impact on your behaviour. Outbursts of what is described as challenging behaviour are more likely to signify frustration as support workers are in control as in “We know you best and what is best for you !” Needless to say this is not an ideal as the client is then labelled as difficult.

Roy McConkey, Professor of Learning Disability Nursing at Ulster University said:

“There has been a great deal of interest in reducing problem behaviours through improving communication and the approach you have developed is an excellent example of what can be achieved with some ingenuity and I guess perseverance ! Good luck with sharing the message, it is much needed.”

2014 Care Act

So how does the 2014 Care Act help those that have been covered in the examples above and what is Makaton's possible role in this?

“The Act also embeds people’s rights to choice, personalised care and support plans, and personal budgets in legislation. A key aim of the Act is to embed and extend personalisation in social care. Personalisation has a wide agenda encompassing universally accessible information and advice, prevention and early intervention, community capacity building, making greater and more creative use of universal services, and tailoring the formal support people need. The evidence suggests people want to be more actively engaged with partners, that services frequently underestimate their willingness, and the potential impact of harnessing this contribution could have huge economic value and lead to better outcomes”

Skills for Care, 2014

The 2014 Care Act also promotes communication with the individual receiving support:

“Person centred care and support planning puts people at the heart of their care and offers them the opportunity to take control and ownership of the process and outcomes of their plan. Everybody will have a personal budget as part of their plan that identifies the cost of their care and support and the amount that the local authority will make available regardless of their care setting i.e. people in residential care will get a personal budget. Person – centred care and support planning refocuses the priority from services to ensuring better lives for people. This means focusing upon the person and their needs and focusing upon existing service provision.

Skills for Care, 2014

Person Centred Planning

The 2014 Care Act emphasises that the individual should be at the centre of the planning process around the support they require. It takes an holistic approach to forming a picture of an individual's support needs. It looks at a person's wellbeing, at how their health and happiness is based on many parts of their life. The whole person is considered, not just their

health or social circumstances. This reflects a move to have agencies in society work closely together – social care, health, education, housing the police and others.

The authors of this article have designed a tool, based on ideas from life coaching, which aims to help individuals make a plan which looks at every area of their life – home, independence, health, interests, friendships, work (either paid or voluntary), family, money, beliefs and physical closeness.

The tool is best imagined as a circle, divided into ten segments, each of which represents one of the areas of life described above. The segments fit together to make one life. The various bits of our life interact. Dealing with only part of a person's life does not make for health and happiness!

A version of the tool using Makaton signs and symbols is designed for use with those who have communication difficulties.

One's needs and circumstances change all the time, so such a plan needs to be regularly reviewed and updated. The key idea is that, while the individual may want to use significant others to help construct the plan, at the end of the day decisions are made by the individual themselves.

In addition, for people who have communication difficulties, the Act speaks of how the local authority has a duty to involve advocacy services. It seems obvious to us, however, that Makaton could provide valuable help both to the person who needs support and to the advocacy services who need help to communicate with the individual.

5. CONCLUSION

It seems clear to the authors that, in some settings, Makaton use does ‘peter out’ as people become older. Mel’s experience would suggest that Makaton is sometimes seen as only appropriate for children.

Some staff and parents went out of their way to prevent the use of Makaton. The opportunity to have those requiring support have a greater control over decisions about their lives is not, sometimes, seen as a priority. As one parent commented, “They’re a bit like children !” Notable exceptions would include the *MyChoicePad* which is seen as improving lives for adults.

Changing the perceptions of carers and parents is a long process. The 2014 Act is described as:

“The most significant reform of care and support in more than 60 years, putting people and their carers in control of their care and support.”

Norman Lamb former Cabinet Minister for Care and Support

Changes of mindset will be required by many involved in care services. Such changes will not simply be about Makaton but about wider issues such as the need for true person-centred approaches to be put in place.

Many things are called person-centred which, in reality, are management centred. For example, one organisation described how they adopted their own approach to person centred planning by sitting clients down as a group and having them decide what THEY wanted to do! Such changes will not be brought about by one person but by various organisations working together. No doubt Makaton, as an organisation, will play their part in that conversation.

The authors of this paper would like to monitor progress on this change of practice and, to that end, we would like to write a further paper describing change and good practice as they happen. We also intend to develop, in consultation with others, the tool described above to help people lead a full life.

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ABOUT THE AUTHORS

Mel O'Neil has used Makaton for fifteen years as parent of a young man with autism and a support worker, and has qualifications in Makaton. She is qualified as a nursery nurse and is passionate about personalisation. Mel broadcasts on community radio and networks with a number of learning disability organisations.

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There is a facebook discussion group where the authors share information and templates, please visit: [Making Personalisation Real](#)

The authors would particularly like to thank Dr Simon Duffy of the Centre for Welfare Reform and Alex O'Neil for their help.

PUBLISHING INFORMATION

Making Freedom Real: Exploring the use of Makaton by adults © Mel O'Neil & George O'Neil 2016

Figure 1 © Simon Duffy 2016

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First published February 2016

ISBN download: 978-1-907790-77-5

25 pp.

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Making Freedom Real: Exploring the Use of Makaton by Adults is published by The Centre for Welfare Reform.

The publication is free to download from: www.centreforwelfarereform.org

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Published by The Centre for Welfare Reform
www.centreforwelfarereform.org

design: henry iles & associates / design@henryiles.com