

Engagement through poetry, a collection of work by young people





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### Introduction

#### Who are Changing Our Lives?

Changing Our Lives is a rights based organisation that works in co-production with disabled people and people experiencing mental health difficulties, of all ages and backgrounds, to deliver solutions to each particular need and strive to achieve positive, person-focussed outcomes around rights, health and social inclusion.

All of our work is rooted in the belief that no one is too disabled to lead an ordinary life. We don't believe disabled people's lives should be limited or defined by disability, we are aspirational in our expectations for them.

Our work takes a community development approach. We believe, and know from experience, that local people and communities are best placed to find their own solutions to local problems, so we work with disabled people of all ages as equal partners to design, deliver and evaluate all of our work.

In March 2016 NHS England commissioned Changing Our Lives through the Learning Disability Engagement Grant to support the involvement of people with learning disabilities who are given the least chance to have their say. The grant aimed for people to be able to:

- Have their experiences listened to
- Be involved in improving healthcare
- Tell NHS England about the issues and challenges that make it harder for them to get the same quality of healthcare as everyone else

Focusing on these aims, the 'Express Yourself' project worked with 16 young people with learning disabilities, and 6 young people with profound and multiple learning disabilities (PMLD), aged 14-19 from Sandwell Metropolitan Borough in the West Midlands. The project had two main aims:

- To explore how poetry can be used with young people with PMLD as an engagement tool and a means of exploring and celebrating their individual communication needs. We were keen to shine a light on this often overlooked group, and show that there are a myriad of ways to engage with these young people.
- To explore how poetry can be used to engage with young people with learning disabilities to find out about their views and experiences of emotional health difficulties and any services that supported them.

As co-production underpins all of our work in Changing Our Lives, we worked with 4 young disabled people from local schools in the design, development and delivery of this project. After being involved in the design of the project, these 4 young leaders were supported to facilitate workshops with their peers so everyone was prepared for working with the artist.

This approach gave the young people experience of project design, group facilitation and public speaking:

"It has been great to see young people take the lead and support the facilitation of the session. Working in co-production gives the young leaders' ideas value and definitely builds their confidence. One of the young leaders would not have done this 12 months ago, he has really enjoyed this whole process with Changing Our Lives and Dreadlock Alien. Seeing his confidence is great."

Staff member from The Westminster School

This poetry book celebrates the voices of young people with PMLD and young people with learning disabilities and shares with the reader their methods of communication and their views and experiences of emotional health and wellbeing.

The poems on pages 12-23 were created by working with 6 young people with PMLD. Spending time with each person and learning how they communicate using sensory objects, words from communication boards, sounds that were converted into beats and rhythms, gradually each poem was born. For instance, in Dale's poem (Listen past the Silence, page 13) Dale is learning to use Picture Exchange Communication System (PECS) to tell staff he wants his sensory objects. The poet used the microphone to engage with Dale as he likes different sounds and touch. Dale grabbed the poet's hand and used it to tap sounds on the microphone and also used his sensory objects to create different sounds. This experience was transformed into a poem that is expressive of Dale's communication.

The poems on pages 24-29 were written by young people with learning disabilities who all use words to communicate. The poems express young people's views of emotional health and emotional health services.

The 4 young leaders were supported to facilitate some initial workshops around the subject of emotional health. The poet then worked with 16 young people, taking the young people's ideas and views from the workshops and mixing them with important words and beat boxing techniques, poetry was born. Young people danced and clapped along performing their own beat boxing and learning about rhythm and rhyme in poetry.

"Beat boxing and spitting is sick! I've had the best day ever!"

The 'Z-Card' in the pull out section at the front of the book illustrates some of the different methods of communication that need to be recognised and valued when embarking on working with young people with PMLD and the innovative and creative approaches that should be explored for a richer engagement experience.





### Who we worked with

Changing Our Lives worked with a total of 22 young people aged 14-19 from across Sandwell Metropolitan Borough in the West Midlands. The individuals were identified through working in partnership with local schools. Each school identified a group of young people with learning disabilities and PMLD. One school identified 6 young people who had experience of using Children's and Adolescent Mental Health Service. (CAMHS) in Sandwell. One of the young people from this group also had experience of the care system.



were from black minority ethnic communities

with a learning disability

with a profound and multiple learning disability



## The Artist

"My artform is of spoken word poetry, beatbox and performance. The art of listening and speaking. This style of spoken word is based in urban hip hop and youth culture. Emerging artforms such as vocal percussion or beatbox can transcend age, cultural and communicational differences. I also personalise the poems to the people and situation. This is referred to as freestyle.

The artform I work within is about communication and we can all do that to some degree. The art is to incorporate that communication in creative, rhythmical and fun way. Working with Changing Our Lives, we notarised words, expressions and emotions for interpretive purposes. This included symbols, words and movements etc.

Through this project, I have been humbled as a practitioner in the art of communication and impressed by the dedication of staff in the pursuit of individual paths of communication for each person. I had to adopt a more peripheral vision to my approach, as the methods of communication used had no set rules or expectations of output. Both technology and the human spirit combined made me realise that communication and emotional well being are intrinsically linked. A smile, a hug, a tone of voice, a space, a routine, a symbol, a laugh all speak without words".

Richard Grant, 'Dreadlock Alien'

# **Beyond Words**

Where hands speak in volumes.

Where sensory will not censor me.

Where eyes tell stories,

Blink to turn the page.

A place where a smile says it all.

Searching for the cause behind the pause,

Read and interpret with signs, symbols and stares.

Behind the carpet of speech we reach the underlay of emotions.

Where language knows no borders or dialect

Where how you are is part of what you say.

Communicate in a different way

Each and every day.

To sharpen my pen you can massage my neck and shoulders.

To ease my pathway you can push aside boulders.

To get my point please look straight into my real eyes.

That's when you realise....

Understand my hands are my punctuation.

Learn our language of interpretation.

8 track, 16 track, 32 track, panels of touch.

Eye gaze that raise aspirations so much.



Listen past the silence,

Echoes of eyes amidst slurred vision.

Then hawk like on task.

Precision.

I hum church songs,

Dale twitched a grin at me.

1,2,3, back to pecs.

Timing, like rhyming in a sequence.

Touch, count, tap and tingle,

Sprinkle a tickle, eyes and thumbs mingle.

We shake, we rattle, we play to and fro.

Tom Tom the human sat nav

Shows Dale the way to go.

We tapped heartbeats on microphone tops.

Frowns every time the vibration stops.

Tap typed touch on paragraphed palms.

We tassle a reached goodbye.

I find out it is hard to hum and smile at the same time.







Mans chillin layed back kickin with his boys.

Playing pure jokes with his blokes and rude machine noise.

Youtube laying down some serious beats.

This part of the meadow is close to the streets.

Three Mandem,

hooded up nice trainers side by side in Tandem.

Not to mention the attention they command from the ladies.





# Language

Kwame works really hard at understanding your speech. If you take a minute to learn he will use it to teach. Picked up the pen again he will draw some.

Favourite word of the day has to be 'Awesome' Kwame every day has something to say at school.

Keeps his calm and keeps his cool.

Listen to the layers within his spoken language.

Like an everything eater with a subway sandwich.

Body language speaks when he starts to dance.

Rhythm and movement start a romance.

Fast reactions he knows what to say.

Thanks for giving me a great Kwame day.





This girl is a legend, her story goes before her.

I have never met her but everyone adores her.

She knows how to tell fact from rumour.

She supplies the school with a daily dose of humour.

Blazing trails and she abseils down stone cliff faces.

Never fails to impress in all of life and it's daily races.

Queen found that bindi bound would never blink or cry, mouse of the third mid brow all seeing eye.

Her character envelops everyone it may find.

Spoke of by her friends they say loving, thoughtful and kind.

If Phoebe was a flavour she could not be sweeter.

I hope one day I will have the opportunity to meet her.

stop

no, not

Nafeesa

Liam

look

more













Sometimes I lead blind to somewhere I do not know.

New things feel strange, like going against the flow.

I like to know what lies behind the door.

Maybe people should talk to me before.

Fun, relaxed, music can help express yourself.

So many different doctors, new ones don't know

All there is to know about my mental health.

Never too late to calculate my mental wealth.

Maybe more comfy seats and more information.

Maybe not to be confused we need clearer communication.

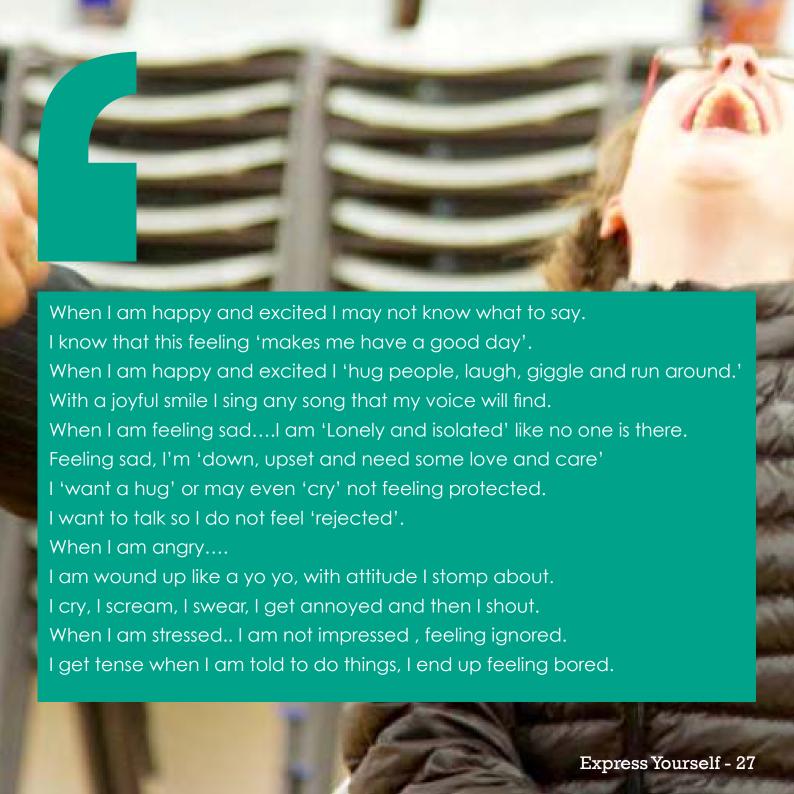
Just placed in a prison of gloom, moved from room to room.

Letters with pages of writing, so hard for me to read.

Babytoys, no picture boards, that's not what I need.











# Conclusion

The way in which society views engagement has changed over the last decade. No longer is it good enough to simply 'consult' with people and ask people what they think. However, despite this change the practice of many healthcare professionals is still out dated and traditional.

The NHS is designed to improve, prevent, diagnose and treat physical and mental health problems. It has a duty to every person that it serves and must respect their human rights. It also has a wider social duty to promote equality through services it provides and to pay particular attention to groups or sections of society where improvements in health and life expectancy are not keeping pace with the rest of the population.

One of these groups are people with learning disabilities and throughout this project we have demonstrated that engagement can be complex, fun and imaginative. It's whatever you want it to be, with whoever you want it to be with. The key is to tap into the way that an individual or group thinks, communicates and is captivated.

'Involvement with arts and culture is crucial to imagination, self-expression and creativity in young people.' Arts Council England The principles of engagement have shifted to an approach that puts people at the heart of the agenda and adopts them as decision makers. This shift in the balance of power accepts that people with learning disabilities are experts in their own circumstances and means that they are equal partners in the design, development, delivery and monitoring of services. This is called co-production.

We need to enable children and young people with learning disabilities to have the resilience to find resources that support them and reinforce their wellbeing, whilst their extended families, communities and services build the social capital to provide these resources in ways individuals determine, shape and value.

Children and young people have taught us how they communicate, shown us how they engage with poetry as one art form, and shared with us some of their thoughts in relation to emotional health. We now need to think creatively when we engage with children and young people and take time and tune into young people's communication if we want to make a sustained and positive difference to their lives.



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- The Westminster School, Rowley Regis
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- Meadows Sports College, Oldbury
- Speech and Language Therapy, Children's Therapies,
   Sandwell and West Birmingham Hospitals Trust
- Dreadlock Alien, Performance Poet



No one's too disabled, No one's too challenging, No one's too complex, ...to live an ordinary life

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