CANADIAN JOURNAL OF
Disability Studies
Published by the Canadian Disability Studies Association · Association Canadienne des Études sur l'Incapacité

The Royal Society of Medicine's 'Medicine and Me: Time for a new approach to adults with cerebral palsy' event review

Melanie Kennedy-Diver
Email: mkennedy2016@hotmail.com

On 7th July 2022, the Royal Society of Medicine held the "Medicine and Me: Time for a new approach to adults with cerebral palsy" hybrid event in London, England. As a student of Disability Studies and a person with cerebral palsy (CP), I approached the event on Zoom expecting a medical model approach to the condition.

The event opened with an initial welcome by news presenter Samantha Simmons. This was followed by the launch of the new brand name of the previous Adult Cerebral Palsy Hub, *UP* – The Adult Cerebral Palsy Hub. Emma Livingstone (Founder and Chief Executive Officer, Adult Cerebral Palsy Hub) shared some of the realities of being an adult with cerebral palsy, stressing the need for more service provision for people with cerebral palsy.

Dr Mark Peterson (Michigan University) discussed the health impacts of having cerebral palsy in adulthood, the increased risks of health conditions, the likelihood of a sedentary lifestyle and mental health conditions. Peterson acknowledged the importance of shifting to the term "lifelong condition" when discussing cerebral palsy. After discussing the increased risk of mental health disorders amongst people with cerebral palsy and the importance of "repackaging" fitness, Peterson concluded with a positive comment on the increasing research into adults with cerebral palsy, increasing from 34 papers in 2009 to 93 as of the end of 2021.

Scarlett Murray, a writer with cerebral palsy, shared her experiences in her presentation, *My life with cerebral palsy.* Murray's personal journey shared her journey with disability, particularly focusing on her teenage years and her attempts to "pass" as non-disabled person.

She described her experiences of not wearing her splints (AFOs) or doing her physiotherapy, but admitted that she did not begrudge younger self for making those decisions. Murray's father made a brief appearance on the presentation video, sharing his experiences of living with and raising a child with cerebral palsy.

Dr Jan Willem Gorter (University Medical Centre Utrecht) continued the discussion of cerebral palsy and mental health. The importance of enhancing positive physical and mental wellbeing over the lifetime was stressed, crucially the development of the individual. Dr Gorter argued that although we tend to view cerebral palsy as an individual condition, it impacts and is impacted by the family and the individual's physical environment. Gorter stressed the need to support families as a whole, rather than just the individual with the disability alone. His most recent research paper, *Correlates of Mental Health in Adolescents and Young Adults with Cerebral Palsy: A Cross-Sectional Analysis of the MyStory Project* indicated an increased risk of anxiety and depression in young adults with CP, many participants showed symptoms of the disorders even without a formal diagnosis. Correlations were family functioning, fatigue and pain. Gorter's research project is part of the MyStory study.

Natalie South-Law (Disability Lead at Sported) brought her own experiences to the event to stress the need for encouraging young people with cerebral palsy to keep active, as sport and gym makes cerebral palsy "better". South-Law recalled how she was removed from Physical Education (PE) classes at her mainstream school to participate in physiotherapy. The physiotherapists were focused on making her walk, a concept, she acknowledged, that is very much the focus of paediatric physiotherapy. This presented medical professionals with a personal insight into how physiotherapy, whilst beneficial, can become focused on the goal of walking and disregard the patient's own wants and needs to reach that target. South-Law argued for the need for more mental health support and connection to disability charities. Mainstream schools, she insisted, should have more inclusion for disabled children to join P.E and join in with their friends, which fosters social skills and teamwork. People should be encouraged to focus on the things they enjoy, with physiotherapists setting personal goals with the individual.

Dr Kirsty Colquhoun, a Consultant Geriatrician, (NHS Greater Glasgow and Clyde) discussed her experiences of CP as a medical professional in her presentation, *When a patient becomes a professional.* Colquhoun described how her disability impacts her approach to patient care. Colquhoun argued that we need more interventions and services for people with cerebral palsy.

Concluding the patients' experience panel, Mrs Jean Martin, a 73-year-old retired podiatrist with CP, presented *I'm Still Here, 70 Years On.* The presentation discussed Martin's life, with a particularly powerful section regarding her pregnancy. Martin confessed that, at the time, she was seen as a "test subject" for what to do when a person with cerebral palsy became pregnant. She admitted to still facing challenges receiving support today, stressing that explaining things openly helps people to gain the support they need. Concluding, Martin acknowledged that cerebral palsy has been a lifelong challenge and spoke about her upcoming speech to medical students, where she hoped to share that adults with cerebral palsy have something to offer society.

After a brief break and welcome back by Samantha Simmons, the event continued with a discussion on disability in the Nordic countries by Dr Elisabet Rodby Bousquet (Lund University, Uppsala University Sweden) in her presentation *The why's and how's of implementing a systematic follow-up of adults with cerebral palsy*. Rodby Bousquet discussed both the advantages and challenges of researching the figures. It was particularly difficult, she acknowledged, because certain areas did not respond to her research survey. The Nordic countries as a collective are, however, expanding their research on the referrals of adults with cerebral palsy. Rodby Bousquet concluded with the strong message that working together helps people to both give and receive better care.

Liz Keenan, a Clinical Nurse Specialist (National Hospital for Neurology and Neurosurgery) and Dr Dipesh Patel, a Psychologist (Department of Neuropsychiatry and Department of Neuropsychology, University College London Hospital NHS Foundation Trust and National Hospital for Neurology and Neurosurgery) presented *Group intervention for cerebral palsy transition.* Keenan and Patel noted that literature on cerebral palsy lacked the lived experiences of the condition. The lived experiences of people with cerebral palsy are particularly crucial as everyone's experience of the condition and the transition between childhood and adulthood is different. Keenan and Patel observed several trends when studying the group. It was felt as though professionals were removing the "voice" from people with cerebral palsy, leading them to disengage with services. Professionals were discussing disabled people in third-person, even when the disabled person was present in the room. There were less appointments for disabled people in adult services, which caused anxiety. In their concluding remarks, Keenan and Patel praised the community and bonds the research participation group had formed. It was acknowledged that the participants felt empowered by the shared experience and space.

Lily Collinson (Programme Director, Gillette Children's Press) brought a new wave of energy as she presented *Future innovations – knowledge and understanding*. Collinson described her experiences as a mother of a son who has spastic diplegic cerebral palsy. Collinson discussed the powerful impact that her book, *Spastic Diplegia Bilateral Cerebral Palsy - A Practical Guide*, has had for both parents of and people with spastic diplegic cerebral palsy. Collinson argued that it is important to have information which relates directly to someone's own specific disability.

Mr Michail Kokkinakis (Consultant Paediatric Orthopaedic Surgeon, Evelina London Children's Hospital) continued the theme of the medical issues in adults with cerebral palsy in his presentation *Management of orthopaedic problems in adult patients with cerebral palsy.* He acknowledged that young adults with CP have important health needs that can become more complex with time. The issue, Kokkinakis, outlined was with transitioning to services for adults. There is a lack of preparation, a lack of expertise, a lack of training and a lack of overall conditions about conditions like cerebral palsy, which are only considered paediatric. People with cerebral palsy are more likely to have orthopaedic problems, but these issues are just the same as those experienced with children with cerebral palsy. The treatments and procedures are the same. There is not a lot of evidence for orthopaedic surgery with adults with cerebral palsy, but there is a lot of literature on joint replacement surgeries because there is a register. Kokkinakis highlighted the aims for the medical community; people with cerebral palsy need to have these orthopaediatric procedures before they reach skeletal maturity and professionals ensure that the transition process is in place. Professionals need to "deal with" under-treated cases, and create MDT teams who can provide a safe, holistic management for the individual. Kokkinakis concluded that appropriate transition needs to be maintained and it is the responsibility of all paediatric medical staff to ensure that adults with cerebral palsy have no musculoskeletal problems in adulthood.

Baroness Fraser of Craigmaddie, (Chief Executive Officer, Cerebral Palsy Scotland) presented *Where do services for adults with cerebral palsy fit within the UK policy context.* The adult service was launched in 2012. Drawing on a study on cerebral palsy and secondary aging by Professor Nicholas Watson, Fraser noted that adults who had been walking and working in their twenties and thirties were no longer walking or working in their fifties. Fraser highlighted the importance of specialist therapeutic input to maintain as independent and functional as possible, but there are neither enough studies or professionals. There are now two guiding policies in Scotland; *The Neurological Framework for Action* and *Healthcare Improvement Scotland, General Standards for Neurological Care and Support,* both of which highlight how adults with cerebral palsy should be treated and how to support them, in theory. Nevertheless, there is a long way to go before the theory becomes the reality, according to Fraser. Fraser paused by reminding the conference how we are stronger together and praised the event for its approach to adults with cerebral palsy. Fraser acknowledged the work of the All-Parliamentary Group with CP, a forum to enable policymakers to understand the issues experienced by individuals with cerebral palsy and their families. Fraser once again reminded us of the strength of voice and campaigning for services.

Emma Livingstone (Founder and Chief Executive Officer, Adult Cerebral Palsy Hub) concluded the event with a brief thank you to all who had attended, discussing the need for investment into people with cerebral palsy. It has been estimated that investing in specialist cerebral palsy services would cost £20 million per year. This could be achieved if 4,000 adults were supported to gain and stay in employment. Livingstone announced that it was believed that this would benefit over 20,000 adults to enter and stay in employment, providing a gross economic benefit to the economy of £422 million. Livingstone highlighted the injustices faced by adults with cerebral palsy and concluded with the purpose of UP and the strength of the cerebral palsy community.

The event's approach to using lived experiences of people with cerebral palsy, parents of people with cerebral palsy and medical professionals created a lively, open space for discussion and learning. It is clear that the barriers to disability have begun to be acknowledged within the medical community. This event has shown the strength of working together to create a complete picture of the experience and effects of cerebral palsy and the importance of acknowledging voice when expressing these experiences. The beginnings of policy in Scotland and the creation of NICE guidelines should change the provision of adults with cerebral palsy, but it is clear that a governmental financial commitment is necessary to provide an adequate level of provision.