

ORAL HISTORY RECORDING SUMMARY

'Fighting for our Rights' project

Surname	Ugle
Given name(s)	Sophie
Date of birth	1960
Place of birth	St John's Wood, London
Date of interview	12 July 2017
Length of interview	01:27:08
Number of tracks	1
Name of interviewer(s)	Jen Kavanagh

Track 1 of 1 [01:27:08]

Sophie Ugle (SU) was born in 1960 in St John's Wood, London to parents Virginia and Said. Father worked as a shipping clerk and a civil servant, mother worked in domestic sector. Attended Christchurch School and Coombe Girls' School in New Malden. Left school age 16 and took a course in buying. Then age 18 took a three year course to become a state registered nurse at St Helier, Carshalton. Talks about career progression. SU had 3 children in 1987, 1989 and 1990 [00:04:50]. Rachel was born in 1990. Talks about Rachel's early life and initial diagnosis of disability. Initially diagnosed with cerebral palsy, but this was dismissed. Rachel has significant delay, doesn't speak or use communication tools. Mentions suggestion of Angelman Syndrome. Explains early symptoms and lack of development. Talks about lack of diagnosis being fairly common [00:11:40]. Mentions positive experience of attending Hobby Horse Opportunity Group in Twickenham. Talks about portage service – supporting parents with helping disabled children develop. Describes Rachel's early education. Mentions Statement of Educational Needs. Talks about speaking to education service at Kingston Council, negative experience [00:17:45]. Rachel attended Corpus Christi in New Malden for nursery. Recognised how severe Rachel's learning disability was. Rachel then attended Dysart School. Talks emotionally about this time. Describes facilities at Dysart including various therapists. Talks about good parent community and FODS (Friends of Dysart School) [00:24:05]. Talks about experience of finding childcare. Recognising the inequality. Mentions National Childcare Strategy. Talks about requesting support from the Malden Centre and the challenges of this. Centre refused to take Rachel due to her disability. Talks about writing report in April 2003, called 'Thinking Big: Childcare for All, how the national childcare strategy is failing disabled children and their families in the royal borough of Kingston-Upon-Thames'. Explains who this was sent to including Edward Davey MP and national charities [00:33:30]. Talks through what the report contains. Describes limited provision available during holidays. SU saw childcare as an opportunity for Rachel to integrate with able-bodied children. Rachel was first disabled child to attend any clubs at the Malden Centre. Talks about importance of integration. Talks about Rachel swimming at Dysart and Malden Centre [00:41:40]. Explains initial contact with Edward Davey MP. Other mothers Sue Baker, Liz Mayes-Reid and Julie T Wallace had also contacted him about service difficulties. Together with SU they established the Kingston Special Needs Project. Explains aims of the group, including access to speech and language therapy. Met at Warren Park Children's Centre [00:48:40]. Talks about mothers going separate ways. SU continued with campaign for childcare. Talks about sitting on a steering group for Thomas Coram Research Unit. Mentions other panel members and aims of group. Talks about Council for Disabled Children [00:55:20]. Further describes SU's report and chasing people for responses.

Positive outcomes include development of Yorda Adventures. Talks about press coverage. Importance of play and social clubs. Mentions speaking at MENCAP conference and campaigning with them [01:02:10]. Talks about awards including from Daycare Trust in 2004, and recognition by Working Families as a pioneering woman alongside Theresa May. Explains how most young people stop attending places like Malden Centre at age 14. Rachel attended Yorda Adventures and specialist care from age 15. Provision shifts to adult services age 18. Talks about Rachel's development of epilepsy [01:08:00]. Talks about Rachel's current living situation with other young adults with profound learning disabilities. Describes activities Rachel attends with support workers, including EnhanceAble. Talks about sensory storytelling at Surbiton Library that SU initiated, pilot project [01:12:45]. Reflects on closure of day centres in Borough. Challenges of integration into the community. Talks about group in Surbiton called Seething Wells and activities they offer. Rachel's involvement. SU and Rachel nominated Seething Wells for award, won both the London and national prizes [01:18:05]. Further describes Seething Wells' work. Talks about Rachel's vocalisation, people staring. Reflects on services, importance of day centres for people with learning disabilities. Describes type of activities that Rachel needs, intensive interaction and sensory activities [01:23:50]. Talks about importance of putting together solid proposals for services. SU feels more should be done to advocate for childcare and specialist activities. More skilled practitioners needed.