

ORAL HISTORY RECORDING SUMMARY

'Fighting for our Rights' project

Surname	Stuart
Given names	Christine Elizabeth
Date of birth	1944
Place of birth	Gorseinon, Wales
Date of interview	19 May 2017
Length of interview	01:39:17
Number of tracks	1
Name of interviewers	Uloma Paris, Jen Kavanagh

Track 1 of 1 [01:39:17]

Christine Stuart (CS) was born in 1944 in Gorseinon, Wales to parents Myra and Norman. Mother was a housewife, father a photographer. Attended school in Wrexham, then university in Aberystwyth. Teacher training at the Institute of London. Taught for two years in Broxbourne, Hertfordshire and then went to America to study at Princeton Theological Seminary in 1969. Met her husband Bruce and got married, a minister. Moved back to London, talks about living at the City Temple in London. CS taught maths for three years in Enfield, then moved on to Bushey to become Head of Sixth Form. Became pregnant with Andrew [00:05:05]. Andrew born in 1978 in Northwick Park Hospital. Talks about birth of Andrew, induced. Midwife disconnected baby from monitor, then later couldn't find heartbeat. Delivered by forceps and required immediate treatment, went to intensive care. Describes experience of being in hospital and scans on Andrew. Talks about receiving physiotherapy for Andrew [00:16:45]. Assessment took place five months after Andrew was born. Diagnosed with cerebral palsy. Talks about early years with Andrew. CS returned to work. Family had car accident, Andrew had convulsion [00:22:50]. Received medication for epilepsy. Talks about nannies. Describes not getting answers from consultants. Talks about attending Spastic Society centre in Watford. Describes Andrew being able to sit, despite staff believing he wouldn't, so left centre [00:29:05]. Talks about feeling bullied by staff. Talks about attending St Michael's special school from age 3. Explains concern over hearing. Family relocated to Sevenoaks, Andrew attended Valence School. Andrew worked with Fergus Anckorn [00:35:30]. Mentions attending Guy's and Great Ormond Street Hospitals. Focussing on Andrew's communication. Describes difficulties with teaching and support at Valence School. Talks about speech therapy assessment. Moved Andrew to Coney Hill and Nash House School in Bromley when Andrew was a teenager [00:43:25]. Speech therapy excellent but no physio. Describes abuse from key worker. New worker introduced Andrew to communication tools. Talks about issues with new teacher, targeted Andrew [00:52:15]. Describes an incident when Andrew choked, made worse by stress from school. Family moved to New Malden when Andrew was age 18. Mentions Kath Turner at Royal Borough of Kingston social services [00:56:10]. Introduced to Independent Living Fund (ILF), and also Kingston's Independent Living Scheme (ILS). Explains how finances worked, including Income Support. Talks about carer called Hazel. Describes Andrew's high pain threshold, determination [01:02:20]. Talks about ILF ending and continuity plan with Kingston Council. Bad experience with social worker. Talks about Carer's Allowance and Assessment. Talks about Disability Related Expenditure (DRE) and Andrew's need for equipment, including communication aids and vehicle. Explains costs of adaptations on car. Challenges of getting funds. Explains then using Motability for support. Explains what DRE is [01:09:05]. Talks about

conversions to the family home and challenges of getting sufficient funds. Social workers were responsible for financial assessments, talks about mistakes being made. Talks about wanting to offer carer a pay rise. Continuity of care important for Andrew. Mentions care plan [01:16:10]. Mentions KCIL and campaigning. CS has worked in advocacy roles for others in the community. Talks about General Election called by Theresa May and concerns for new future [01:20:30]. Tells story about assessment in Sevenoaks. Describes caring for Andrew being an ongoing uphill battle. Talks about communicating with Andrew, very draining. No professional support for Andrew now he's an adult. Describes Andrew's current condition including spondylitis. Ongoing fight for care and medical treatment [01:27:05]. Talks about change in local authority support, much better 20 years ago. Describes concern for future of social care. Talks about physical strain of caring for Andrew on CS. Ends by reflecting on worries about reversal of social care provision.

End of recording [01:39:17]