



Image: the Burleigh Family Taking Tea by Charles Henry Harrison Burleigh (1947) Museum of the Home

Dr Julia Bell (1879–1979)

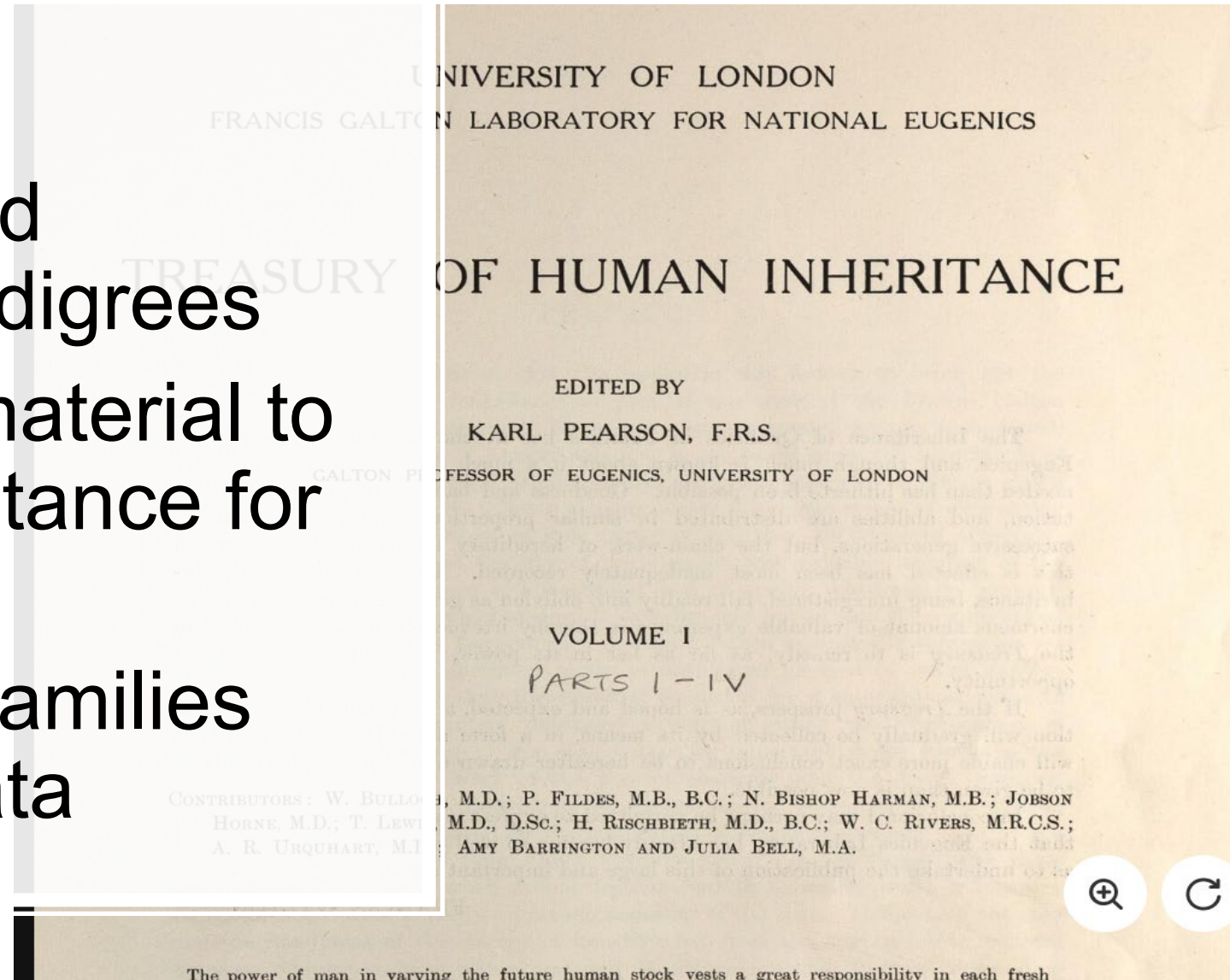


- 1898-1901 Mathematics at Girton College, Cambridge
- 1907 MA from Trinity College, Dublin
- 1908-1914 work on medical genetics under supervision of Karl Pearson
- 1914 London School of Medicine
- 1920-1933 Return to Galton Laboratory (funded by MRC)
- Wrote 13 of 24 vols of *The Treasury*
- 1933-1944 MRC scientific staff
- Sex-linked conditions (colour blindness and martin-bell – later fragile-X syndrome)



The Treasury of Human Inheritance 1909-1958

- Included published and unpublished family pedigrees
- Designed to provide material to illustrate human inheritance for students of heredity
- Bell had to work with families to obtain and verify data



1. Demarcation of genetic influences from environmental conditions and

1. Demarcation of individual genetic susceptibility due to their categorisation as part of a group from ways of living as a member of that group

	Mean age of onset			Differences		
	Parents	Single members	Parents and singles	Mothers and singles	Fathers and singles	
Muscular dystrophy	(82) 28.05	(48) 15.52	+ 12.53	+ 10.83	+ 13.57	
Huntington's chorea	(233) 38.87	(151) 32.97	+ 6.30	+ 5.02	+ 7.41	
Peroneal atrophy	(81) 26.39	(63) 20.52	+ 5.87	+ 4.98	+ 7.22	

	Source of genetic determination	Age of onset			Age at death		
		No.	Mean	Standard deviation	No.	Mean	Standard deviation
Sex-linked	Pedigrees	173	5.298 ± 0.311	4.089 ± 0.220	111	18.041 ± 0.720	7.585 ± 0.509
	Ped. with R' and single cases	456	5.421 ± 0.225	4.795 ± 0.139	173	17.908 ± 0.505	6.638 ± 0.337
Recessive	Pedigrees	199	10.088 ± 0.666	9.399 ± 0.471	68	29.441 ± 2.212	18.239 ± 1.504
	" d	85	9.736 ± 0.974	8.976 ± 0.688	32	27.607 ± 3.605	20.393 ± 2.549
	" v	112	10.491 ± 0.919	9.724 ± 0.650	34	24.706 ± 2.645	15.424 ± 1.870
	Ped. with R' and single cases	338	11.375 ± 0.560	10.302 ± 0.396	85	28.500 ± 1.931	17.091 ± 1.380
	" d	174	11.609 ± 0.769	10.150 ± 0.544	44	29.091 ± 2.989	19.827 ± 2.114
Dominant	" v	162	11.235 ± 0.823	10.476 ± 0.582	37	24.112 ± 2.459	14.956 ± 1.739
	Pedigrees	199	18.605 ± 0.927	13.079 ± 0.656	84	50.367 ± 2.585	23.690 ± 1.828
	" d	111	19.392 ± 1.306	13.729 ± 0.921	42	48.065 ± 3.732	24.188 ± 2.639
R'	" v	88	17.614 ± 1.294	12.139 ± 0.915	42	52.819 ± 3.543	22.958 ± 2.506
	Pedigrees (all males)	187	6.566 ± 0.466	6.018 ± 0.329	29	18.293 ± 1.254	6.753 ± 0.887
Single cases	"	279	9.056 ± 0.378	9.494 ± 0.409	60	17.594 ± 1.439	11.455 ± 0.918
	" d	209	8.194 ± 0.592	8.553 ± 0.418	45	19.167 ± 1.772	11.895 ± 1.253
	" v	50	12.900 ± 1.672	11.822 ± 1.182	—	—	—

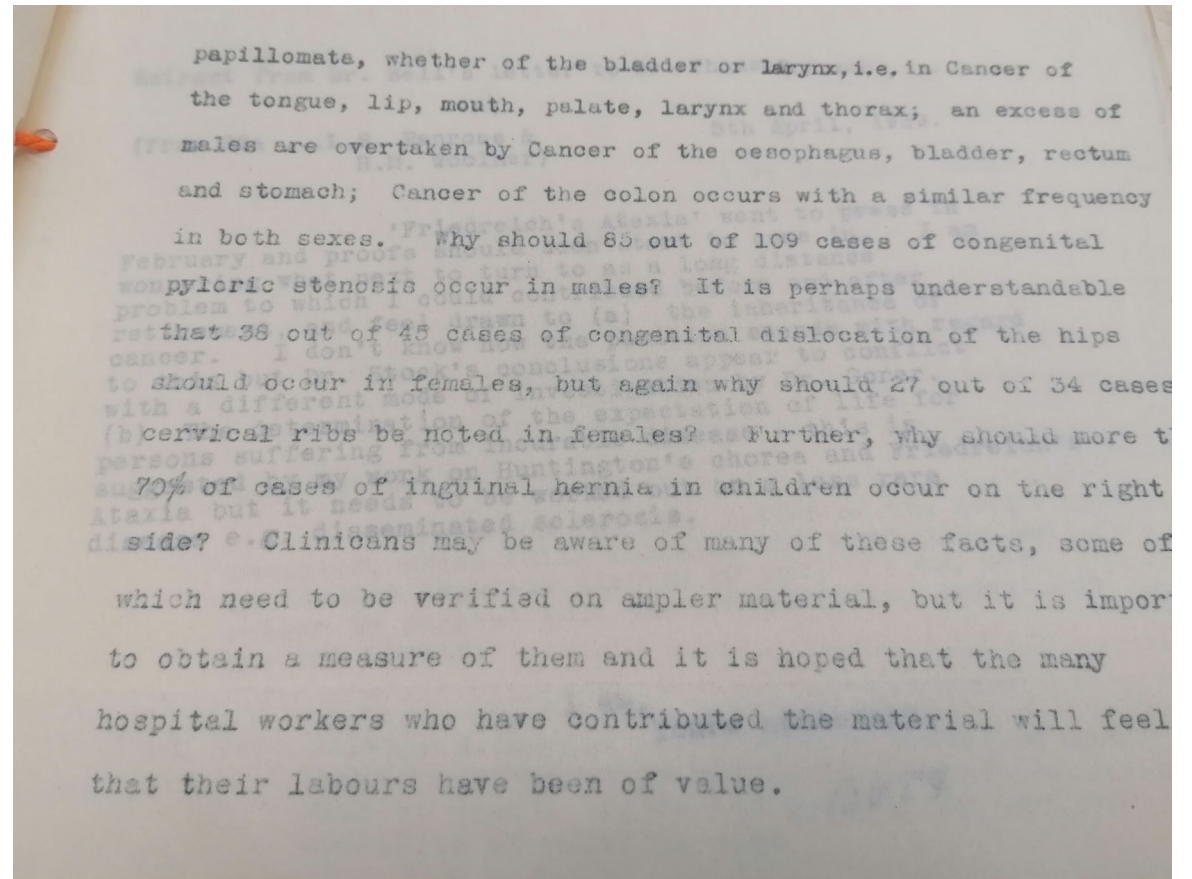
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Table 4 demonstrates higher age of onset for parents than 'singles'. Table 5 gives the mean age of onset and age at death in the different cases.

36 out of 45 cases of congenital dislocation of the hips should occur in females, but again why should 27 out of 34 cases of cervical ribs be noted in females? Further, why should more than 70% of cases on inguinal hernia in children occur on the right side?

Extract from Dr J. Bell's annual report – 1932, National Archives, FD 1/591



papillomata, whether of the bladder or larynx, i.e. in Cancer of the tongue, lip, mouth, palate, larynx and thorax; an excess of males are overtaken by Cancer of the oesophagus, bladder, rectum and stomach; Cancer of the colon occurs with a similar frequency in both sexes. Why should 85 out of 109 cases of congenital pyloric stenosis occur in males? It is perhaps understandable that 36 out of 45 cases of congenital dislocation of the hips should occur in females, but again why should 27 out of 34 cases of cervical ribs be noted in females? Further, why should more than 70% of cases of inguinal hernia in children occur on the right side? Clinicians may be aware of many of these facts, some of which need to be verified on ampler material, but it is important to obtain a measure of them and it is hoped that the many hospital workers who have contributed the material will feel that their labours have been of value.

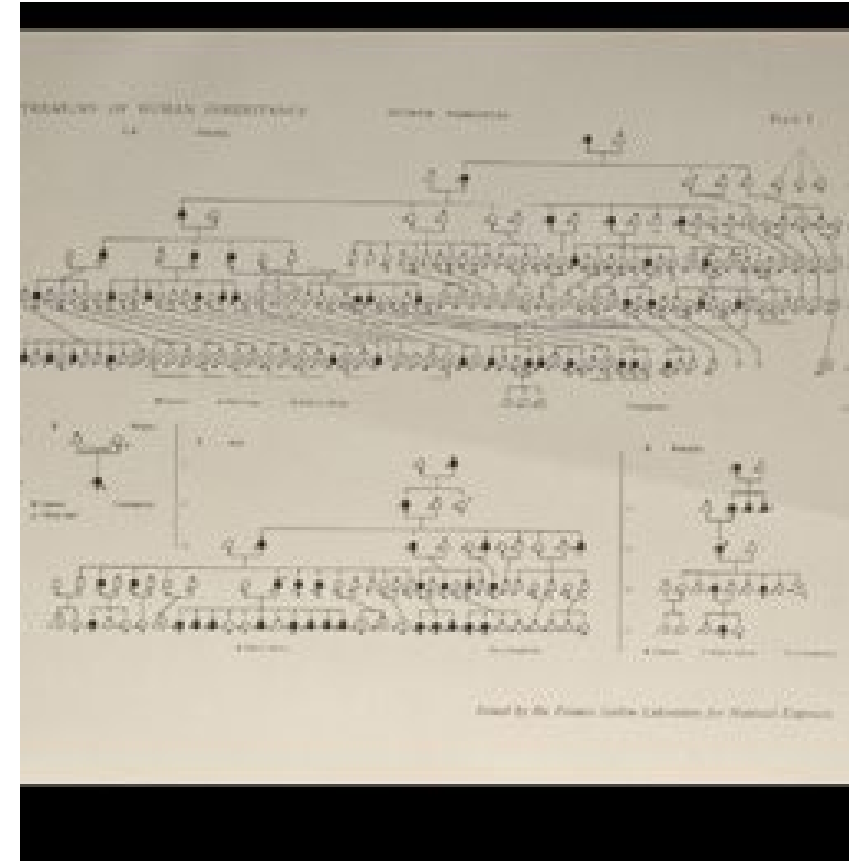
Categories used to organize data for statistical analysis

Increased focus on potential role of the environment

Epidemiological categories linked to the politics of inequality

E.G. Sex and race differences in Glaucoma

- Bell emphasized the influence of gender differences over sex, differences but made the opposite move when considering race, emphasizing the influence of genetics over cultural factors



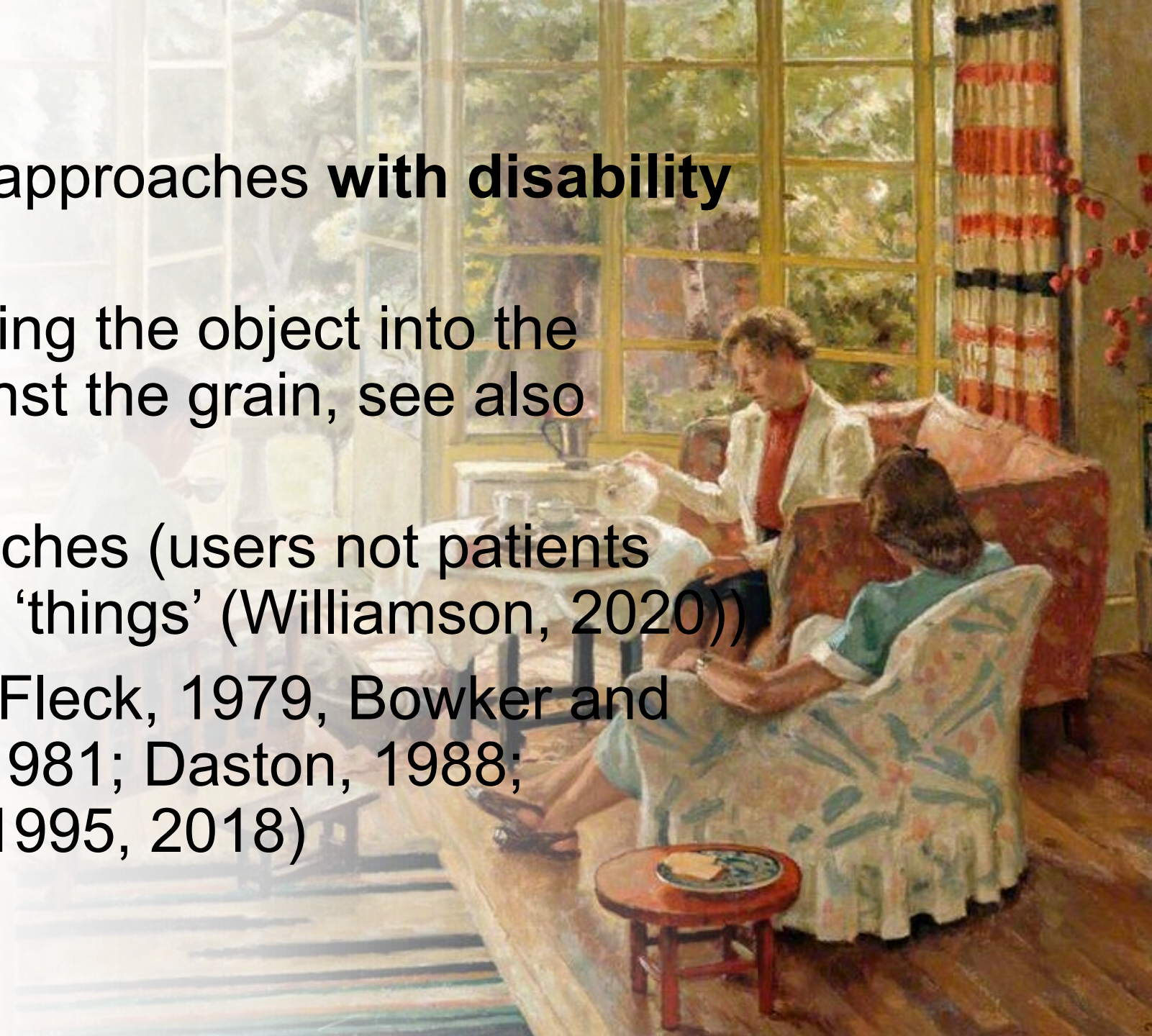
Disability was central to eugenics as a necessary concept, motivation, and problem.

- Disability central to 'evaluative nature' of eugenics (Rembis, 2018)
- Foregrounding disability within genetics 'blurs the boundaries between eugenics and medical genetics' (Schmidt, 2020)
- Genetics and eugenics entangled during interwar era (Bland and Hall, 2010)
- Only through mutated genes could researchers attempt to understand 'normal' function (Fox-Keller, 2000)

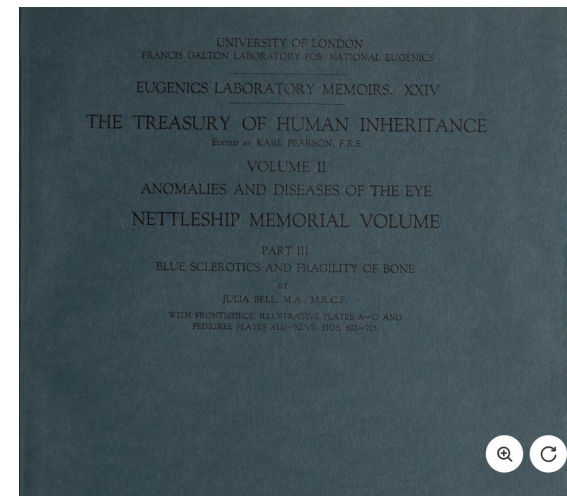


Amalgamation of three approaches **with disability history**

1. **Medical history** (turning the object into the subject by reading against the grain, see also Stoler, 2008)
2. **STS & SCOT** approaches (users not patients and the use of disability 'things' (Williamson, 2020))
3. **History of Science** (Fleck, 1979, Bowker and Star, 1999; McKenzie, 1981; Daston, 1988; Hacking, 1990; Porter, 1995, 2018)



Mosaic approach



- 1928 volume on ‘Blue sclerotics and fragility of bone’
- Disability as a positive asset
- Cure versus loss
- Tension between the clinical gaze and lived experience
- Active resistance and pushback from disability history perspective



When Categories Constrain Care

Investigating Social Categories in Health Norms
through Disability History 1909-1958

Existing research and digitised material

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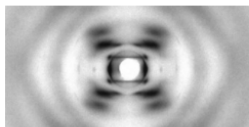
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Investigating history of eugenics around University College London (UCL)

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Historicizing the binary between genetic and acquired disablement through contrasting investigations to reveal a broader history of categorizing inequality in

1. Investigation of the scientific research into genetic disability that took place in the first half of the twentieth-century.

2. Investigation of how these categorized were used in compensation for acquired disability through archival research (focus on mining)

Shifting categories

- The scientific investigation of disability gave credence to other salient categories
- This reveals the epistemological power of categorisation in its creation of disability as difference that mattered and could be counted and classified.
- 'What social groups are classified, corralled, coerced, and capitalized upon so others are free to tinker, experiment, design and engineer the future?' (Benjamin, 2019)



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