		Quantitative	Qualitative			
Authors/year	Country	methodology	methodology	Participants	Purpose of study	Themes
Aston, Breau and	Canada		Feminist post-	37 in total:	To better understand how children with	Impact of HCW's
MacLeod; 2014 (32)			structuralist; semi-	8 children with IDs;	intellectual disability, their parents and	assumptions on
			structured interviews;	17 parents;	nurses experience care during	care quality.
			thematic analysis	12 nurses	hospitalisation.	Reliance on
						parental
						presence.
						Importance of
						understanding
						the child and the
						ID.
Atz et al; 2011 (20)	USA	Multicentre		120 children;	Outcomes after specific cardiac surgery,	• Benefit of labels.
		prospective and		96 with Down syndrome	comparing children with and without	Importance of
		retrospective cohort		24 without Down	Down syndrome.	understanding
		study		syndrome		the child and the
						ID.

Table 1: Included studies, with authors, country, methodology, participants, purpose of study, and main findings/themes

Brown and	United	Semi-structured	28 participants:	Describe the experiences of children,	•	Reliance on
Guvenir; 2008 (31)	Kingdom	interviews; thematic	13 carers of children with	their families and staff during		parental
		analysis	learning disability	hospitalisation.		presence.
			13 nursing staff		•	Listening to
			2 children with learning			parents.
			disability		•	Importance of
						understanding
						the child and the
						ID.
Croot; 2012 (35)	United	Constructivist;	12 in total from 9 families:	Provide evidence of the care needs of	•	impact of HCW's
	Kingdom	interview; thematic	11 parents; 1 grandparent	Pakistani parents with a child with		assumptions on
		analysis		learning disabilities.		care quality.
					•	Listening to
						parents.
					•	Importance of
						understanding
						the child and the
						ID

Desai et al; 2014 (21)	United	Single centre;	107 children;	Determine if Down syndrome is a risk	•	Benefit of labels.
	Kingdom	Retrospective cohort	67 with Down Syndrome	factor in the early postoperative period	•	Importance of
		study	40 without Down	following specific cardiac surgery.		understanding
			syndrome			the child and the
						ID.
Fudge et al; 2010 (23)	USA	National database;	45 579 children;	Describe the postoperative morbidity and	•	Importance of
		Retrospective cohort	4350 with Down syndrome	mortality rates for children with Down		understanding
		study.	41229 without Down	syndrome undergoing cardiac surgery.		the child and the
			syndrome			ID.
			syndrome			ID.
Furukawa et al;	Japan	Single centre;	syndrome 235 children;	Evaluate mortality and postoperative	•	ID. Impact of HCW's
Furukawa et al; 2013 (22)	Japan	Single centre; Retrospective cohort		Evaluate mortality and postoperative outcomes after cardiac surgery in	•	
	Japan		235 children;		•	Impact of HCW's
	Japan	Retrospective cohort	235 children; 8 with Down syndrome	outcomes after cardiac surgery in	•	Impact of HCW's assumptions on
	Japan	Retrospective cohort	235 children; 8 with Down syndrome 227 without Down	outcomes after cardiac surgery in	•	Impact of HCW's assumptions on care quality.

ID.

Graham et al;	USA	Single centre;	3437 anaesthetic events in	To determine the utilization of	•	Impact of HCW's
2009 (26)		Retrospective cohort	children;	anaesthesia resources by children with		assumptions on
		study	479 had complex special	complex special health care needs.		care quality.
			health care needs	Included children with developmental	•	Reliance on
			2958 did not have special	disorders such as Down syndrome.		parental
			health care needs.			presence.
					•	Listening to
						parents.
Gupta et al; 2014 (24)	USA	National database;	2815 children;	Evaluate morbidity and mortality	•	Impact of HCW's
		Retrospective cohort	121 with Down syndrome	associated with ECMO in children with		assumptions on
		study.	2694 without Down	Down syndrome and heart disease.		care quality.
			syndrome.		•	Importance of
						understanding
						the child and the
						ID.
Lal et al; 2013 (25)	India	National database;	64 children;	Investigate outcomes from specified	•	Impact of HCW's
		Retrospective case-	32 with Down syndrome;	cardiac surgery in children with Down		assumptions on
		control study.	32 matched controls.	syndrome and compared to children		care quality.
				without Down syndrome.		

Malviya et al;	USA	Single centre;	Random sample of	To compare pain assessment and	•	Impact of HCW's
2001 (30)		Retrospective cohort	children who had spinal	management practices in children with		assumptions on
		study	fusion	and without cognitive impairment.		care quality.
			19 had cognitive		•	Importance of
			impairment			understanding
			23 did not have cognitive			the child and the
			impairment			ID.
Morabito et al;	United	Single centre;	173 children with	Compare the outcomes of surgery for	•	Impact of HCW's
2006 (28)	Kingdom	Retrospective cohort	Hirschsprung's Disease;	Hirschspung's Disease in children with		assumptions on
		study	17 with Down syndrome	Down syndrome to those without Down		care quality.
			156 without Down	syndrome.	•	Importance of
			syndrome			understanding
						the child and the

ID

Pratt, Baird and	United	QI audit and	QI audit and interviews	Experience of 52 children	Evaluate the effectiveness of a quality	•	Impact of HCW's
Gringras; 2012 (33)	Kingdom	evaluation		with neurodevelopmental	improvement programme to improve the		assumptions on
				problems;	care experience during hospitalisation for		care quality.
				Pre change interviews:	children with learning difficulties, autism	•	Listening to
				20 staff and 4 families.	and challenging behaviour.		parents.
				Post change interviews:		•	Importance of
				20 staff			understanding
				8 parents			the child and the
							ID
Travassos, van	The	Single centre;		149 children with	Compare the outcome of surgical	•	Impact of HCW's
Herwaarden-	Netherlands	Retrospective cohort		Hirschsprung's disease;	treatment for Hirschsprung's disease in		assumptions on
Lindeboom and		study		20 with Down syndrome;	children with and without Down		care quality.
van der Zee; 2011				129 without Down	syndrome.	•	Importance of
(29)				syndrome			understanding
							the child and the

ID

Valkenburg et al;	The	Single centre;	45 neonates having same	To compare postoperative analgesic pain	•	Impact of HCW's
2011 (27)	Netherlands	Retrospective cohort	surgical procedure	scores and management between		assumptions on
		study	15 with Down syndrome;	neonates with and without Down's		care quality.
			30 without Down	syndrome.	•	Importance of
			syndrome.			understanding
						the child and the
						ID
Van Driest et al;	USA	Single centre;	121 children having	Compare opioid administration after	•	Impact of HCW's
2013 (34)		Retrospective cohort	specific cardiac surgery;	cardiac surgery in children with and		assumptions on
		study	44 with Down syndrome;	without Down syndrome.		care quality.
			77 without Down		•	Importance of
			syndrome.			understanding
						the child and the
						ID