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

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

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

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

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

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

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

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