




Disrupted Lives: Complying with the social order of the ward



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Parent Participation – Central Tenet of Children’s Nursing

- WHY ?
 - Detrimental effects of hospitalisation upon children (Spence, 1947; Robertson, 1958 etc)
 - Research on maternal deprivation (Bowlby,1951)
 - Numerous governmental reports (1946; 1959; 1971, 1976; 1991,1993; 1996)
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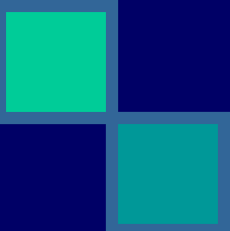



Partnership With Parents

- Children Act, 1989
 - Consistent with consumerism ideology
 - Rights and role of the consumer (DoH, 1997;1998;1999a, 199b)
 - Patient-centred service (DoH, 2000)
 - Professional nursing bodies and consumer lobby groups
 - Collaboration and partnership key terms - policy documents
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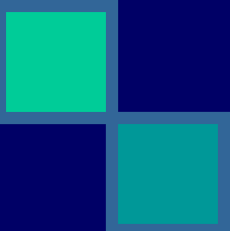



Aims of the Study

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- To examine the conditions, effects and management of parent participation.
 - To understand how parents, their children and nurses negotiate roles and relationships within the hospital setting.
 - To generate a grounded theory which explains the process of parent participation.
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Design

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- Grounded theory method
 - In-depth Interviews, Observation, Questionnaires
 - 4 wards - 2 hospitals- London
 - Nurses aged 23- 40 years (n= 12)
 - Parents aged 30-56 years (n=11)
 - Children with acute and chronic illness aged 7-14 years (n=11)
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Finding a Balance






Finding a Balance - Child

- 
- **Having a problem**
 - **Relying on friends**
 - **Fears and uncertainty**
 - **Disruption**
 - **Investigations and treatments**
 - **Needing parents**
 - **Control and permission**
 - **Adapting**
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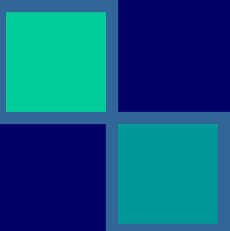


“Fitting In” With the Ward Order


- Being a ‘good’ patient
 - Seeking information
 - Seeking permission for actions
 - Operating within boundaries
 - Complying with rules and regulations
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“Toeing the Line”

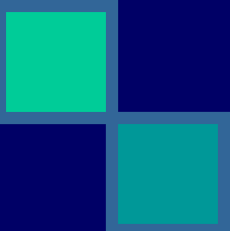


Yeah, I think I'd like to make some decisions, like when I get up or don't get up...the nurse said to me the other day, right we're going to get you out of bed and I thought hold on a minute I don't want to get out of bed, I'm not going to (indignant tone of voice) I mean they try to understand but really you're the only one who knows how you feel (Hope-13 yrs)






Instilling Discipline




They (children) can keep you up watching the television all hours of the day and night if they can... and they won't have a dinner but they will have a pudding so its up to us same as teachers. It's up to us to ... to instil discipline and respect in children... with children I say "no I'm sorry television goes off ...visitors are gone by seven what you do at home is your business but what we do in hospital is mine (Senior Staff Nurse 7B.31)



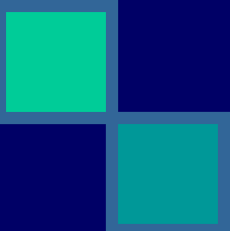



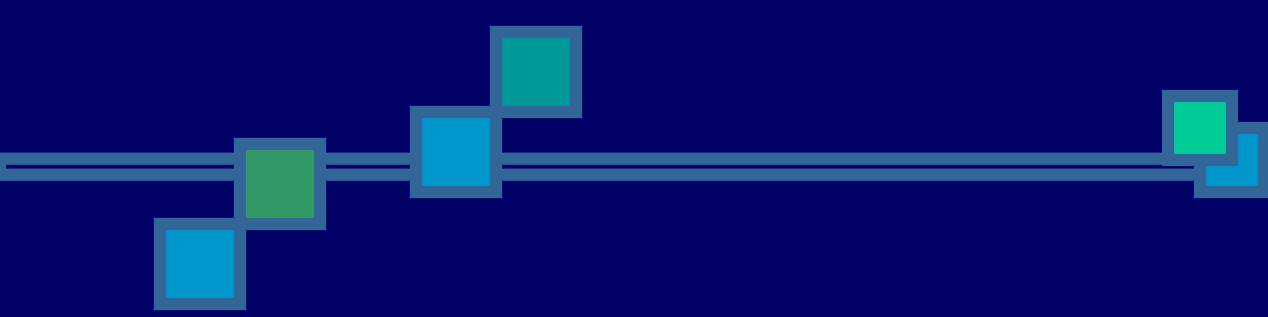
Findings: Parents' perspectives

- Balancing usual responsibilities
 - Fears and uncertainty
 - Needing support
 - Conflict of care-giving
 - Ambiguous boundaries
 - Nurses not being there
 - Child being neglected
 - Burden of caring
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Nurses Not Being There

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- They were running around and you couldn't find one. I was pacing up and down trying to find one and I couldn't find one at all. They were all up that end somewhere (M5B.60)
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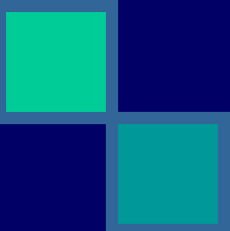


I wasn't quite sure of what I was allowed to do and what I wasn't allowed to do, whether really the nurses should have been doing some or the things or not but I suppose that should have been set out from the beginning...what did they expect us to do (M9C.47)






Parents have to stay

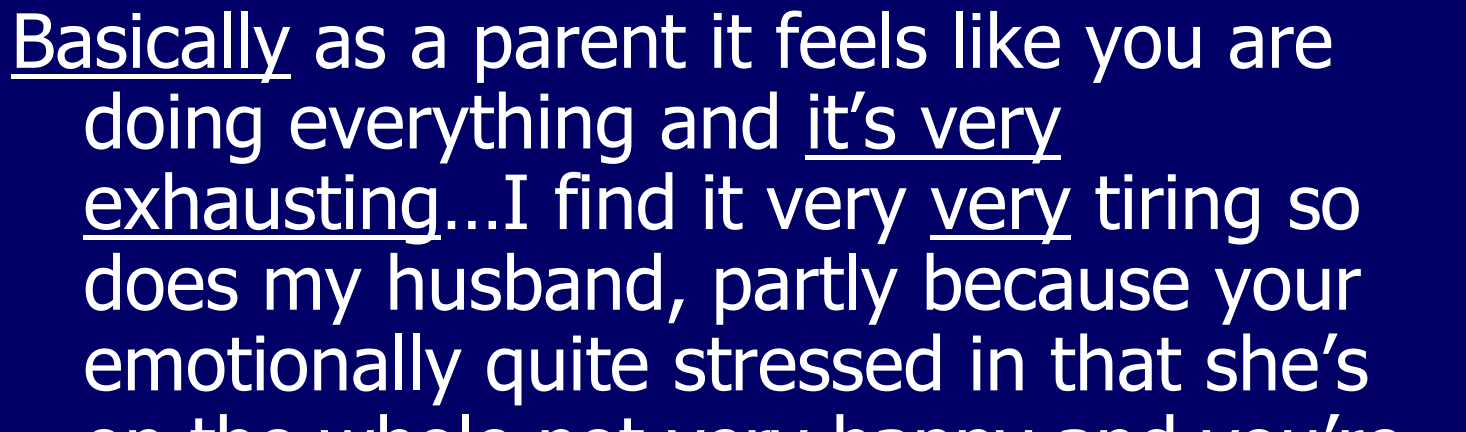


I think everything is changed
so much more...for
parents...they've got to stay
(M1A.89)



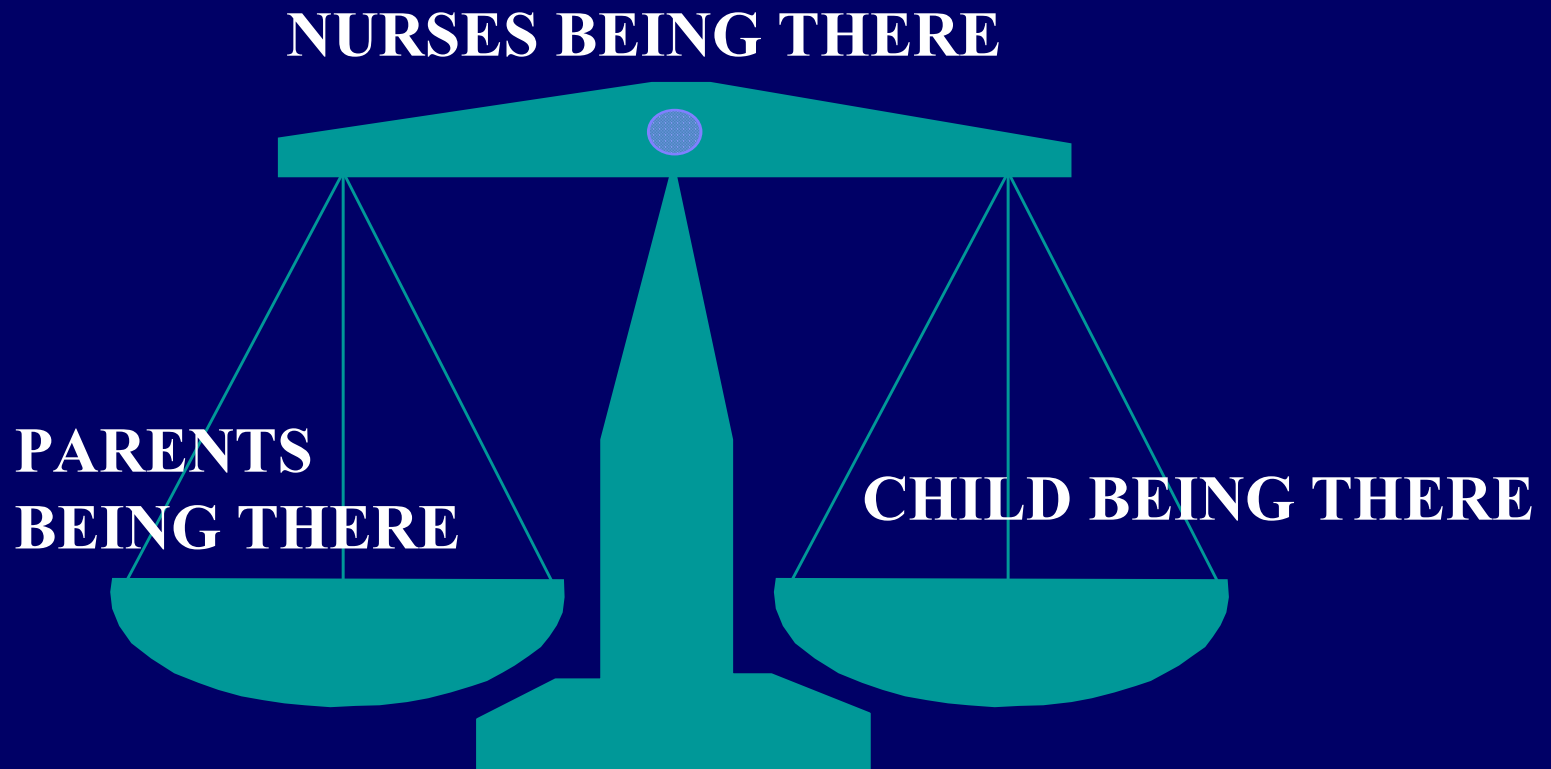


Burden of Caring




Basically as a parent it feels like you are doing everything and it's very exhausting...I find it very very tiring so does my husband, partly because your emotionally quite stressed in that she's on the whole not very happy and you're worrying about the fact of the operation tomorrow or whatever happens to be but partly cos you are basically doing all the caring (M10C.27)

Fit With Parents' and Childrens' Expectations






Nurses' perspectives

- Assuming parents will be there
 - The 'good' parent
 - Parents' role deficit
 - Expecting parents to be there and to do care
 - Nurses relying upon parents
 - "Fitting in" with parents
 - Being a facilitator rather than a 'doer'
 - Teaching and supporting
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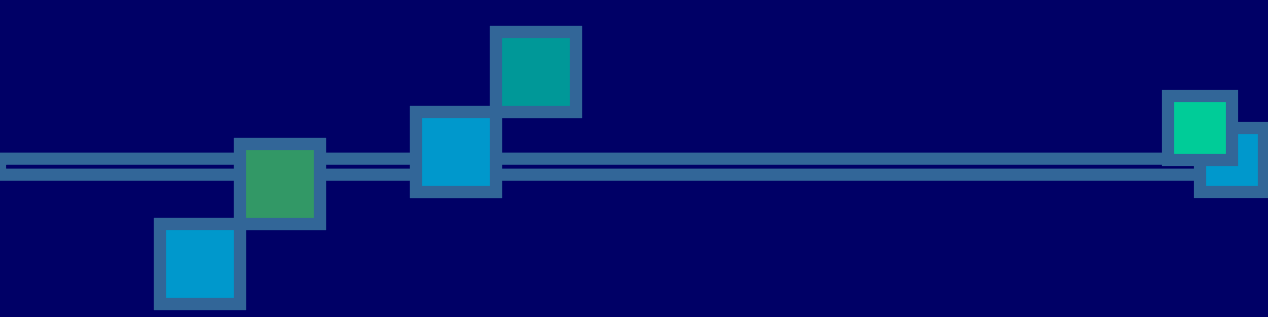
Relying upon parents

- **Nurses unable to be there**
 - Organisational factors (e.g. staffing levels, patient acuity, technical care, admin duties, clerical duties)
 - 'Everyday childcare' not nurses role
 - Role of other personnel (e.g. HCA, play specialist, volunteer staff)
 - Depriving parents of their role
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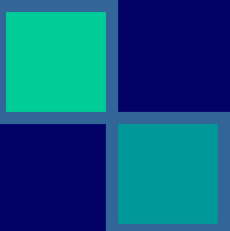


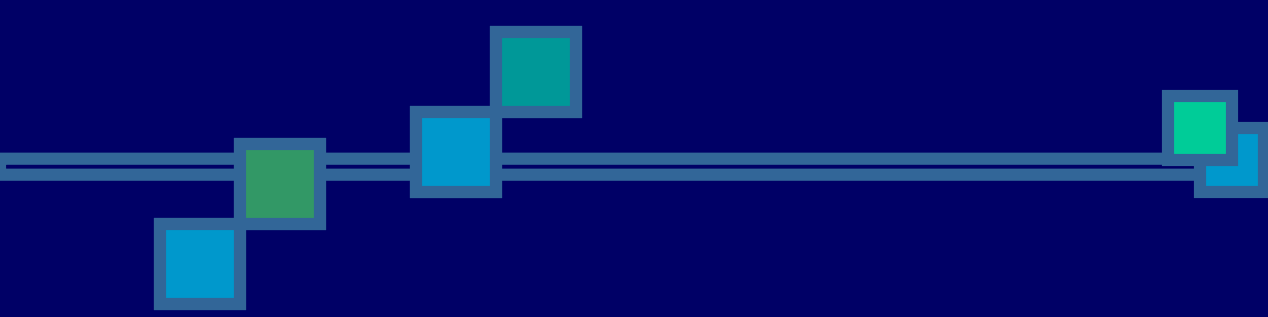
Nurses' Socialising Parents to Expected Role

- Using inclusionary actions
 - assessing parents / situation
 - encouraging parents
- Using exclusionary actions
 - labelling parents
 - avoiding parents


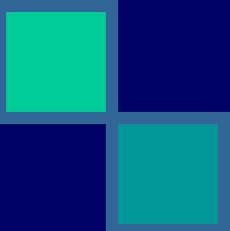


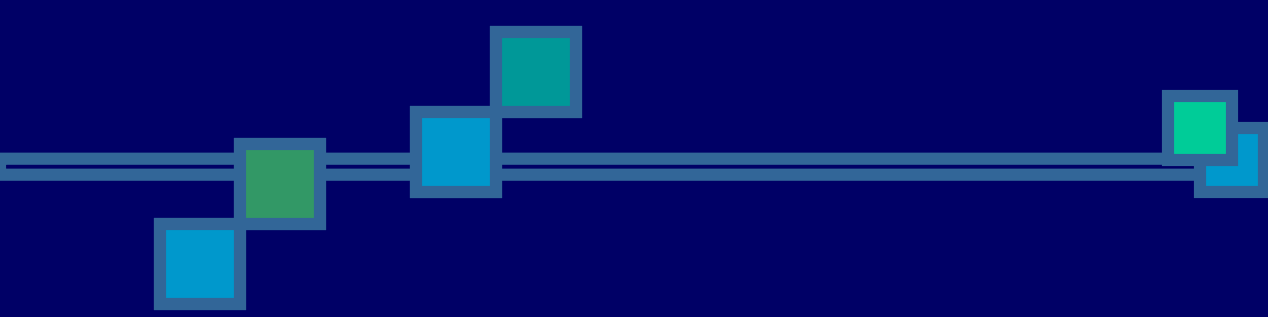
I think it's for the nurse to actually facilitate the stay of the parent, not to be the doer, but to work alongside parents and to be an informer... keep the parents and the patient up to date with what's going on and be their assistant (N9C.31)






We assume when they are here that they will get on and do it and we don't always ask them if they want to do it. We take it for granted that they will do it (N4A.8)



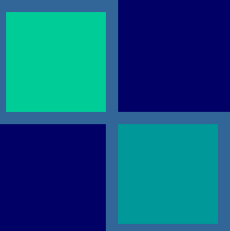


You see most of the things parents can do and if the parents are there to look after the child we don't have to sit with them... but most of the time we don't spend that much time with them... We rely a lot on the parents and the families to be there (N11C.59-60)






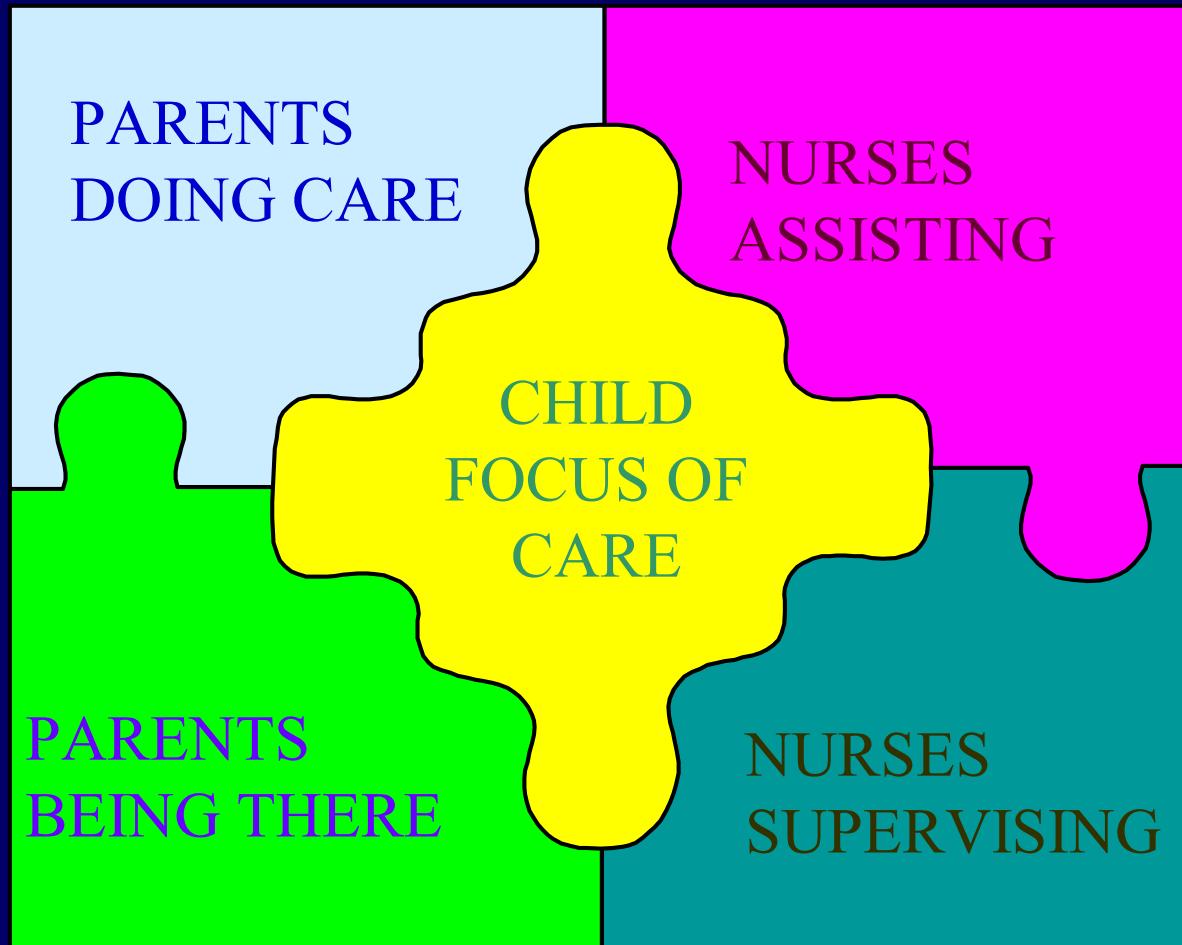
“Doing your bits”

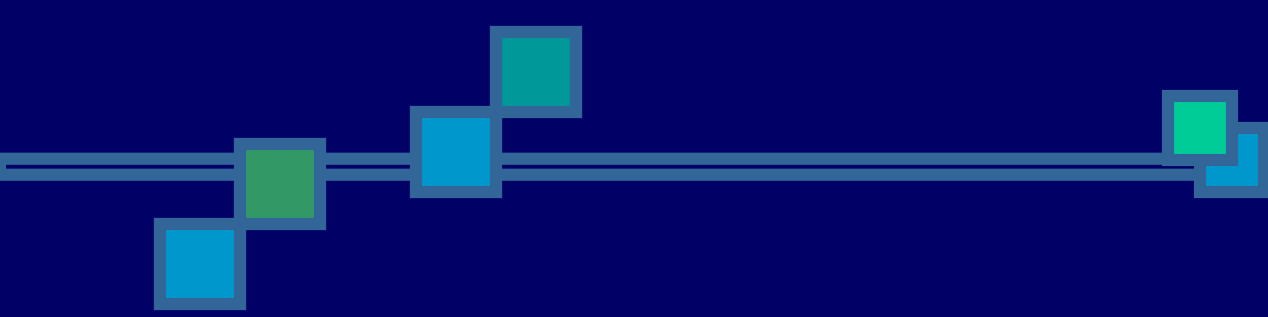


It's lovely when you've got a parent there 24 hours a day because it's really family centred care and you just go in and do your bits (N15D.29)


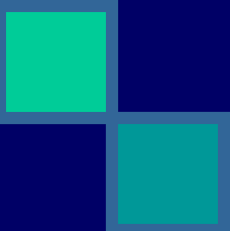


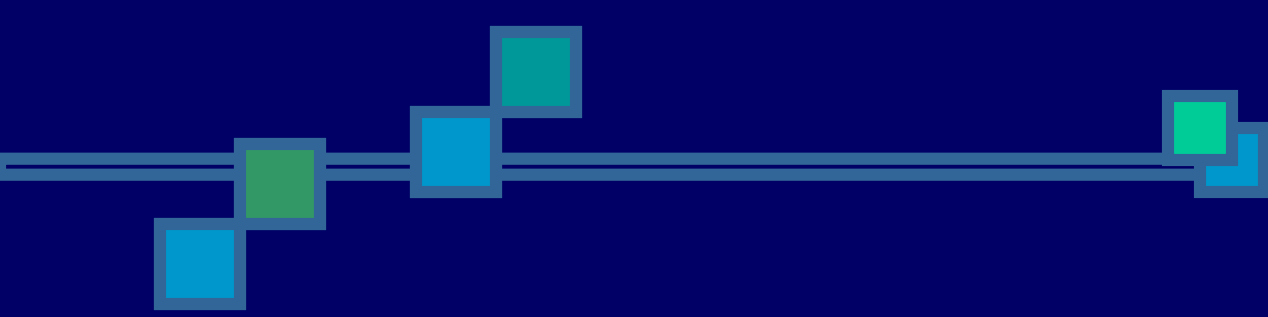
Fit with Nurses' Expectations






I don't know if it's ignorance or if it's nerves or its just laziness... it's something I have never been able to fathom out (N7B.18)



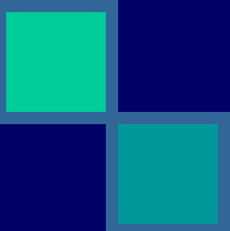


It's difficult as well when you hear
in handover “Oh this family a
nightmare” (*she laughs*) cause
people do say that and oh I don't
want to look after them
(N12C.53)






Pretending it's a partnership

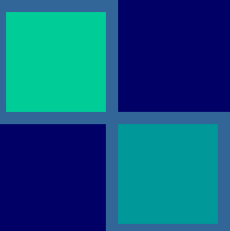


I like the idea of partnership/ family centred care. In the right environment it works very well but I think an awful lot of pressure is put on to the nurses to get everything done and pretend that we're doing a partnership (N13D.106)






Lack of Responsibility




Partnership can be destructive and...it is how nurses use it cause they have abused it in the sense that it is an escape.... escape from entering into a relationship maybe and entering into the practical things with the parents and....maybe it is contributing to the lack of responsibility and the accountability on the nurses part (N10C.46)



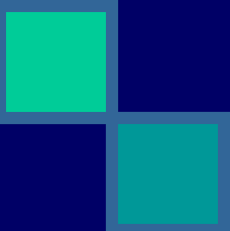



What This Means...

- Partnership ideal rather than reality
 - Promoted by educationalists
 - Reinforced by hospital policy
 - Not expected by parents
 - Control and permission
 - Redundant role
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What This Means...

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- Participation influenced by needs of the hospital organisation
 - Socialisation of parents and children to compliant role
 - More about administrative efficiency rather than consumer empowerment
 - Disruption of the family unit
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Next Steps

- Move on from blaming the individual rather than the system
 - Reconsideration of relevance of studies on maternal deprivation
 - Reconsideration of appropriateness of the partnership model
 - Consideration of the family – organisation interface
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- Thank you for your time and attention.
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