

Practice Standards for Paediatric Renal Social Workers

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Background

- In 1996, Practice Standards devised by Judith Argles
- Standards created for the following areas covered by renal social workers:
 - General Standards for Chronic Kidney Disease
 - Acute Renal Failure
 - Parents Considering Live Donation
 - Post Transplant Support
 - Cystinosis & Nephrotic Syndrome
 - Children on Haemodialysis
 - Guidelines for Children on End-Stage Programme
 - Pre-Emptive Transplantation

Standards provide a practical tool

- Standards useful when I took up post in 1998
- Provided a frame of reference when I became involved with families
- Ensured that thorough psychosocial assessment completed
- Realisation that previous skills acquired in generic childcare social work insufficient

Review of practice standards

- Standards specific to Nottingham Unit and devised in 1996
- UK Paediatric Renal Social Work Group decide that standards need to cover all units
- September 2010 Meeting to discuss plan
- Paediatric Renal Social Worker Role Varies!
- I volunteer to begin project
- Presentation today is work in progress

Why is it important to devise practice standards?

- Psychosocial Support difficult to quantify and explain
- We can draw on vast experience of current and previous social workers about “what works”
- New social workers need guidelines
- Important to evaluate our work against agreed standards of practice
- Important for role to be recognised as an integral, professional role within Paediatric Units

What informs renal social work in the UK?

- All social workers have to register with the General Social Work Council and follow their codes of conduct and practice
- Social Workers employed by local councils follow their guidelines e.g. Nottinghamshire County Council - Children & Young People's Services. Social Care & Health Standards. April 2009
- National Service Framework 2006 - Kidney Disease and The National Service Framework for Children, Young People & Maternity Services
- Guidelines devised in individual renal units
- Sharing of practice amongst paediatric renal social workers

Chronic kidney disease - key stages where social work involvement required

- Diagnosis
- End-stage programme
- Active treatment e.g. starting dialysis
- Transplant Preparation - including live donation
- Post transplant support
- Preparation for Transition to adult renal unit

Childhood development stages where social work support may be required

- Diagnosis at birth
- Active treatment in early infancy
- Starting school
- Moving on to secondary education
- Coping with puberty and exams
- Planning for leaving school
- Understanding disease progression and its relationship with developmental stages

Where do we begin?

- Case histories and reflect on practice
- Understanding of child development and how chronic kidney disease impacts on this process
- Draw on colleagues' experiences about practice that works well
- Prevention better than cure - social workers should be integral to work and avoid crisis referrals
- Feedback from families

Minimum standards (1)

- Be informed and understand the diagnosis
- Home visits
 - Soon after diagnosis
 - When active treatment starts
 - To discuss transplantation, including live donation
 - Post-transplant support
 - Transition planning
- Maintain regular contact and meet during out-patient appointments
- Liaise regularly with renal team
 - Stay informed about medical situation
 - Inform team of any relevant family dynamics

Minimum standards (2)

- Act as an advocate for the family
- Discuss plans at psychosocial meetings and co-ordinate home visits
- Offer link to another family
- Regularly review needs of patient and family within the team and (if relevant) with outside agencies e.g. Social services, schools
- Ensure families are advised about benefits and charitable organisations.

Case Study 1

- Baby diagnosed ante-natally with posterior urethral valves
- Introduced to family after baby is born
- Family have mixed emotions
- Baby has other health problems
- Support continues throughout early infancy
- Preparation for live donation
- Support to family as they apply for place at specialist school

Case Study 2

- Baby seriously ill at six months old with meningitis
- Baby survives with chronic kidney disease and learning difficulties
- Dialysis required at two years old
- Transplant fails
- Dialysis required
- Further failed transplant
- Child now 15 and facing long term dialysis
- Preparation for an uncertain future

Summary

- The case studies highlight issues regarding disease progression
- Also highlight impact on child development
- Loss is key issue that comes up regularly and needs to be considered in practice standards
- Examining our current and previous practice will shape our standards
- Case histories are a good starting point!

And Finally!

- The Challenge - to devise standards that can be applied in all units
- The Obstacles - variation in the paediatric renal social worker role
- Moving Forward - we should aim high and think about best practice
- Being Realistic - changes will take time to implement and local constraints in individual units
- Outcome - to devise minimum standards of social work practice with suggestions from families about what works
- It is work in progress and we welcome your feedback and suggestions!