groups and should be supported by the eye care providers in each district.

Conclusion

The framework in this article outlines some basic considerations for establishing community action for children with cataract while at the same time ensuring that the infrastructure is in place to meet the need for services. It proposes that the starting point should always be an understanding of the barriers, as this will help to make the approach appropriate to each setting.

References


10 Key Messages on Childhood Cataract: What all Health Workers Need to Know

1. Cataract can occur in babies and children - it is not limited only to the elderly.
2. A child may be born with cataracts (congenital cataract) or s/he may develop cataracts during the first few years of life (developmental cataract).
3. Cataracts can run in families, and more than one child in the same family can be affected.
4. Any parent or carer who notices a white spot in their child’s eye(s), or who thinks the child cannot see properly, should be taken seriously.
5. All children with blindness and/or cataract should be referred to an eye doctor for detailed eye examination, diagnosis and treatment as soon as they are detected.
6. Congenital blindness is treatable when it is due to cataract.
7. Surgery is the only treatment for cataract in children.
8. Treatment of cataract in children is a matter of urgency as early surgery increases the likelihood of better vision. The cataract does not need to ‘mature’. If treatment is delayed there is a risk of amblyopia and irreversible visual impairment or blindness.
9. After cataract surgery children may need to wear spectacles. This also applies to babies.
10. Long term follow-up is essential (unlike cataract surgery in adults), to monitor the vision, to change the glasses, and to manage complications.

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Abstract

Engaging families in health services research on childhood visual impairment: barriers to, and degree and nature of bias in, participation

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AIM: To investigate the barriers to, and degree and nature of bias in, participation in health services research by parents of children with visual impairment. METHODS: Parents of children newly diagnosed with ophthalmic disorders at Great Ormond Street Hospital, London, participated in a study to elicit their health service experiences and needs through a postal questionnaire survey followed by in-depth interviews. The participating and non-participating families were compared at different stages of recruitment, according to sociodemographic and clinical characteristics. RESULTS: 20%(55) of all eligible families could not be invited to participate because of out of date contact details for either the family and/or family doctor in the hospital and/or community record systems. Completed questionnaires were received from 67%(147/221) of contacted families, although only 6% actively declined to take part. Compared to non-participating parents, those who took part were more likely to be white British, from higher socioeconomic groups, have English as their main language, and have no other visually impaired family members. There were no significant differences according to the clinical characteristics of their affected children. CONCLUSIONS: Families from socioeconomically deprived and ethnic minority groups are likely to be less visible than others in health services research on childhood visual impairment. Geographical mobility in families of young children with visual disability poses a potentially important obstacle to engaging them in research on their experiences of health services. These findings indicate the importance of addressing potential biases in the design and interpretation of future studies, to ensure equity in recommendations for policy and practice, and in implementation of services.