Knowledge, Attitude and Practice Survey Tool for Intellectual Disability (KAP-ID)

Lakhan R¹

¹Dr.P.H. Epidemiology Candidate, Department of Epidemiology and Biostatistics, School of Health Sciences, College of Public Services, Jackson State University, Jackson, MS, USA

ABSTRACT

Background: Community based rehabilitation approach is very popular in providing rehabilitation services to the people with intellectual disability in low and middle income countries. It is useful to assess level of knowledge, attitude and practices of parents and relatives of people with intellectual disabilities for strategic planning of the program.

Method: series of meetings, focus groups and in-depth interviews with the professionals employed in community based rehabilitation project and workers, and community members were conducted. Common questions around the issues related with intellectual disabilities were collected and discussed. These questions were refined with consultation, references with existing literature and field testing.

Result: We have developed and tested a Knowledge, Attitude and Practice survey tool for Intellectual Disability (KAP-ID) in a resource poor setting of a middle income country, India. This tool contains fifteen questions.

Conclusion: This brief survey tool is helpful in assessing knowledge, attitude and practices of parents, relatives and also of the community on intellectual disabilities. Information gained through the survey on KAP-ID found to be useful in designing the behavioral, awareness, educational, health promotional, and interventional program for the population with intellectual disabilities in rural poor settings.

Key words: intellectual disability, survey, tool, public health, communitybased rehabilitation, low and middle-income country

> 1) medical, 2) educational, 3) economic and 4) social or community intervention. In medical intervention, person with ID receives appropriate medical services. Family members are educated and prepared to assist in intervention. Larger community including parents, relatives, villagers, government functionaries such as teachers, community workers and other members are educated under the section of social intervention.⁷ For any such program, it is very crucial to understand mind set of the parent's, relatives of the

*Corresponding Author: Ram Lakhan

Dr.P.H. Epidemiology Candidate, Department of Epidemiology and Biostatistics, School of Health Sciences, College of Public Services, Jackson State University, Jackson, MS, USA Email: ramlakhan15@gmail.com

Citation

Lakhan R. Knowledge, attitude and practice survey tool for intelectual disability (KAP-ID.) Nepal Journal of Medical Sciences 2014;3(1):22-25.

Background:

Intellectual disability (ID) is a public health problem.¹⁻² Therefore, it is better to apply public health, behavioral and health promotional strategies in intervention. Presently community based rehabilitation (CBR) approach is very popular in low and middle income countries.³⁻⁶ It applies several public health approaches in promoting health and prevention of diseases. CBR have four major components

intellectual disabled people and community around them.⁸⁻ ⁹ CBR program are very flexible and can be customized as per the local needs.^{7, 9-10} Following this philosophy, a survey can be planned to understand knowledge, practice and attitude of different groups in order to develop a culture sensitive and holistic interventional project plan.¹¹⁻¹³ People with disabilities face higher rate of disparities in accessing health services.¹⁴ It is also very important to understand stigma that is most commonly associated with intellectual disability.¹⁵⁻¹⁷

Objective: design a knowledge attitude practice survey tool for intellectual disability for low and middle income country.

Methods: KAP-ID was developed in a very poor district of Madhya Pradesh state of India. A non-government organization Ashagram Trust (AGT) located in Barwani district had three community based rehabilitation / health projects. There was a need of understating parent's views, and practices on ID. Author of this research facilitated discussion in CBR core team. Focus groups and in-depth interviews were used with CBR team, CBRWs and community members. CBR team comprised various professionals from different fields such as psychiatrist, clinical psychologist, specialists in intellectual disabilities, orthotic-prosthetic engineers, social workers, physiotherapist, and other community workers. This team was interacting with ID population and their parents/relatives at regular basses. Common questions were collected after the discussion in this team. Then those questions were field tested by CBRWs and professionals of the CBR team. This was done with series of meetings at AGT, and in community, and findings of its use in another study are incorporated in this paper.¹¹

Results: KAP-ID is a useful survey tool to use with parents and relatives of ID (Table -1). This was effectively used in another study.¹¹ This tool measures 15 major issues those are commonly faced in LAMI countries when dealing with children with ID, more specifically in rural, impoverish and less educated communities. This tool can be implemented by any person who has basic ability of reading. Specific training is not required. It takes around 15 minutes to survey one participant. Survey tool should be administered on both parents separately to understand each parent. All questions have four answer choices, including one option as other. This tool is designed on the qualitative research methods.¹⁸⁻¹⁹ Tool can also be used with community members by skipping specific questions intend solely for parents.

Discussion: Administration of this survey tool in parent interviews itself develops some form of openness on the

topic between service providers/interviewer and parents. This exercise helps in involving parents in interventional process. Involvement of parents in community programs for intellectual disabilities affects its outcome positively.²⁰ KAP-ID found effective in measuring the knowledge, attitude and practices of parents towards their children with disabilities. Which greatly enhanced understanding of CBR team in dealing several management, service related issues with ID. Use of this tool assisted CBR team to modify and plan appropriate and cultural sensitive strategies of developing awareness and involving community in process of rehabilitation.¹¹ Involvement of parents, and community in rehabilitation process helps in spreading awareness on ID issues.^{11, 21-24}

 Table 1: Knowledge, Attitude and Practice Survey Tool for

 Intellectual Disability (KAP-ID)

Knowledge, Attitude and Practice Survey Tool for Intellectual Disability (KAP-ID)							
Name of Child:							
Age	Age/D.O.B:Sex:						
Level of Disability:							
Information Provider:							
Address:							
Interviewer: Date:							
No	Questions	Options	Selection				
1.	Is your child born with intellectual disability due to your sin in previous life?	Yes No No Idea other					
2.	Can faith healing make child with intellectual disability all right?	Yes No No Idea Other					
3.	Can a person with intellectual disability manage his / her own life?	Yes No No Idea Other					
4.	Should parent allow their ID child to play with their non-disabled peers?	Yes No No Idea Other					
5.	Do you think a child with intellectual disability benefits from school?	Yes No No Idea Other					
6.	Do you think appropriate training improves condition of a child with intellectual disability?	Yes No No Idea Other					

Do you think a person with intellectual disability can marry and enjoy her/his life?Yes No No Idea Other2.Do you think a person with intellectual disability can look after his/her property?No No Idea Other3.Do you think a child with 9.No intellectual disability can learn new skills with stepwise training?No No Idea Other4.Do you think a child with intellectual disability can be trained to speak?No No Idea Other10.intellectual disability can be trained to speak?No No Idea Other11.Is your child with intellectual disability have disability certificate?No Idea Other Yes12.Do you involve your child with intellectual disability in household activities?No No No Idea Other13.What is the life span of a person opinion?More Less No Idea Other14.What are the causes of intellectual disability?Postnatal Perinatal All above No Idea15.How do you manage behavior problems?ignore Make understand Train other			
Do you think a person withNo8.intellectual disability can look after his/her property?No Idea Other9.Do you think a child with skills with stepwise training?Yes No9.Do you think a child with intellectual disability can learn new skills with stepwise training?No Idea Other10.Do you think a child with intellectual disability can be trained to speak?No11.Is your child with intellectual disability have disability certificate?No Idea Other Yes11.Is your child with intellectual disability have disability certificate?No Idea Other Yes12.Do you involve your child with activities?No13.What is the life span of a person opinion?More Less No Idea14.What are the causes of intellectual disability?Postnatal Perinatal All above No Idea15.How do you manage behavior problems?Postnatal Physically punish Leave/ ignore Make understand Train other	7.	intellectual disability can marry and	No No Idea
Do you think a child with intellectual disability can learn new skills with stepwise training?No No Idea 	8.	intellectual disability can look after	No No Idea
Do you think a child with intellectual disability can be trained to speak?No No Idea 	9.	intellectual disability can learn new	No No Idea
 11. Is your child with intellectual disability have disability certificate? No Idea Other Yes No 12. Do you involve your child with intellectual disability in household activities? No Idea Other Normal 13. What is the life span of a person with intellectual disability in your opinion? No Idea Other Prenatal 14. What are the causes of intellectual disability? No Idea Postnatal All above No Idea 15. How do you manage behavior problems? Make understand Train other 	10.	intellectual disability can be trained	No No Idea
 Do you involve your child with intellectual disability in household activities? What is the life span of a person with intellectual disability in your opinion? What is the life span of a person More Less No Idea Other What are the causes of intellectual disability? What are the causes of intellectual disability? What are the causes of intellectual All above No Idea Physically punish Leave/ ignore Make understand Train other Any other observation made by interviewer while collecting 	11.	-	Yes No No Idea
 What is the life span of a person What is the life span of a person with intellectual disability in your opinion? Itess No Idea Other Prenatal Postnatal Perinatal All above No Idea Physically punish Leave/ ignore More More More More More More Less No Idea Physically punish Leave/ ignore Make understand Train other 	12.	intellectual disability in household	Yes No No Idea
 14. What are the causes of intellectual disability? 14. What are the causes of intellectual disability? 14. Prenatal Postnatal Perinatal All above No Idea Physically punish Leave/ ignore ignore Make understand Train other 15. How do you manage behavior ignore Make understand Train other 	13.	with intellectual disability in your	Normal More Less
Physically punish Leave/ 15. How do you manage behavior ignore problems? Make understand Train other Any other observation made by interviewer while collecting	14.		Prenatal Postnatal Perinatal All above
Any other observation made by interviewer while collecting	15.		Physically punish Leave/ ignore Make understand Train

Conclusion: KAP-ID was found easy to use, and useful in CBR programs for understanding mindset of people and planning interventional strategies. Tool also found feasible to implement, culturally sensitive, and useful for professionals in various rehabilitation settings.

Nepal Journal of Medical Sciences | Original Article

Acknowledgement: The author sincerely thanks to Ashagram Trust Barwani and their financial partner Action Aid for allowing him to conduct this research. He also thanks to all CBR workers, CBR professionals, and all parents of people with intellectual disabilities for their participation in the research.

Conflict of Interest: declared none

References:

- Lakhan R. Social, Environmental and Biological Determinants of Cerebral Palsy in Children with Intellectual Disabilities (ID) in India. Nepal Journal of Epidemiology 2013; 3: 262-68. <u>http://dx.doi.org/10.3126/nje.v3i3.9187</u>
- Lakhan R. Intelligence quotient is associated with epilepsy in children with intellectual disability in India. Journal of Neurosciences in Rural Practice 2013; 4: 408-12.

http://dx.doi.org/10.4103/0976-3147.120241

- Lakhan R. Inclusion of Children with Intellectual and Multiple Disabilities: A Community-Based Rehabilitation Approach, India. Journal of Special Education and Rehabilitation 2013: 14: 79-97. http://dx.doi.org/10.2478/v10215-011-0035-1
- Kumar SG, Roy G, Kar SS. Disability and rehabilitation services in India: Issues and challenges. Journal of Family Medicine and Primary Care 2012; 1: 69-73. <u>http://dx.doi.org/10.4103/2249-4863.94458</u>
- 5. Cameron DL, Nixon S, Parnes P, et al. Children with disabilities in low-income countries. Paediatrics & child health 2005; 10: 269-72.
- Alam KJ, Bari N, Khan MA. Community based rehabilitation practices and alleviation of poverty of people with disabilities in Bangladesh. In Workshop on Community-Based Rehabilitation (CBR) and Poverty Alleviation of Persons with Disabilities. Bangkok. 2005 Available at, (<u>http://www.dpiap.org/national/pdf/</u> community_based_rehabilitation.pdf)
- Carter EW, Trainor AA, Ditchman N, et al. Communitybased summer work experiences of adolescents with high-incidence disabilities. The Journal of Special Education 2011; 45: 89-103. http://dx.doi.org/10.1177/0022466909353204

- Ahmad I, Qadir S, Yasir M, et al. Knowledge, Attitude and Practice Related to Occupational Health and Safety among textile mills workers in Dera Ismail Khan. Gomal Journal of Medical Sciences 2012; 10: 222-26.
- Robertson J, Emerson E, Hatton C, et al. Efficacy of Community-Based Rehabilitation for Children with or at Significant Risk of Intellectual Disabilities in Low- and Middle-Income Countries: A Review. Journal of Applied Research in Intellectual Disabilities 2012; 25:143-54.

http://dx.doi.org/10.1111/j.1468-3148.2011.00638.x

- Morrissey C, Taylor J, Bennett C. Evaluation of a therapeutic community intervention for men with intellectual disability and personality disorder. Journal of Learning Disabilities and Offending Behavior 2012; 3: 52-60. <u>http://dx.doi.org/10.1108/20420921211236933</u>
- Lakhan R, Sharma M. A study of knowledge, attitudes and practices (KAP) survey of families toward their children with intellectual disability in Barwani, India. Asia Pacific Disability Rehabilitation Journal 2010; 20: 101-17.
- Simkhada PP, Shyangdan D, Teijlingen VER, et al. Women's knowledge of and attitude towards disability in rural Nepal. Disability and Rehabilitation 2013; 35: 606-13. http://dx.doi.org/10.3109/09638288.2012.702847
- Kaur G. Public awareness, attitudes and beliefs about intellectual disability: a Sikh perspective. Doctoral dissertation, UCL, University College London 2011;
 Available at, (<u>http://discovery.ucl.ac.uk/1338985/1/</u> <u>Gurpreet%20Kaur%20DClinPsy%20Vol%201.pdf</u>)
- 14. Ouellette-Kuntz H. Understanding health disparities and inequities faced by individuals with intellectual disabilities. Journal of Applied Research in Intellectual Disabilities 2005; 18: 113-21. <u>http://dx.doi.org/10.1111/j.1468-3148.2005.00240.x</u>
- Scior K, Addai-Davis J, Kenyon M, et al. Stigma, public awareness about intellectual disability and attitudes to inclusion among different ethnic groups. Journal of Intellectual Disability Research 2012; 57: 1014-26.
- 16. Sheridan J, Scior K. Attitudes towards people with intellectual disabilities: A comparison of young people from British South Asian and White British

backgrounds. Research in developmental disabilities 2013; 34: 1240-47. http://dx.doi.org/10.1016/j.ridd.2012.12.017

- 17. Antony PJ. How Do Social, Cultural and Educational Attitudes towards Disability Affect Families of Children with Disabilities and There by Affect the Opportunities and Daily Experiences of People with Disabilities in Kerala-India? Doctoral dissertation, Washington State University 2009; Available at, (<u>http://www. dissertations.wsu.edu/Dissertations/Summer2009/p_ antony_090109.pdf</u>)
- Sofaer S. Qualitative research methods. International Journal for Quality in Health Care 2002; 14: 329-36. <u>http://dx.doi.org/10.1093/intqhc/14.4.329</u>
- Ritchie J. The applications of qualitative methods to social research. Qualitative research practice: A guide for social science students and researchers 2003; 24-46.
- 20. Einfeld SL, Stancliffe RJ, Gray KM, et al. Interventions provided by parents for children with intellectual disabilities in low and middle income countries. Journal of Applied Research in Intellectual Disabilities 2012; 25: 135-142. http://dx.doi.org/10.1111/j.1468-3148.2011.00678.x
- 21. Coles S, Scior K. Public attitudes towards people with intellectual disabilities: a qualitative comparison of white British & South Asian people. Journal of Applied Research in Intellectual Disabilities 2012; 25: 177-88. http://dx.doi.org/10.1111/j.1468-3148.2011.00655.x
- 22. Reichow B, Servili C, Yasamy MT et al. Non-Specialist Psychosocial Interventions for Children and Adolescents with Intellectual Disability or Lower-Functioning Autism Spectrum Disorders: A Systematic Review. PLoS medicine 2013; 10:1-27, e1001572.
- 23. Green S, & Baker B. Parents' emotion expression as a predictor of child's social competence: children with or without intellectual disability. Journal of Intellectual Disability Research 2011; 55: 324-338. http://dx.doi.org/10.1111/j.1365-2788.2010.01363.x
- 24. Estes A, Vismara L, Mercado C et al. The impact of parent-delivered intervention on parents of very young children with autism. Journal of autism and developmental disorders 2014; 44; 353-365. http:// dx.doi.org/10.1007/s10803-013-1874-z