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Original Research

The Effectiveness Of Family Empowerment In Increasing The Independence Of The Daily Living Activities Of Children With Intellectual Disability

Prasaja Prasaja[1,] Linda Harumi[2*]

[1,2] Department of Occupational Therapy, Poltekkes Kemenkes Surakarta, Indonesia

ABSTRACT

Background: *Intellectual Disability (ID) is a disability characterized by significant limitations in intellectual functioning and adaptive behavior in many social skills and practical daily skills, including activities of daily living (ADL). To train ID children to independently carry out these activities, it is necessary to empower families (increase knowledge, attitudes, and skills of parents in handling ID children at home) so that the handling of ID children can be optimal. The purpose of this study was to analyze the effectiveness of family empowerment through training and monitored home programs on increasing ADL independence for ID children.*

Methods: *This research was conducted using a quasi-experimental one-group pretest and posttest. The data analysis in this study is the Paired Samples T-test. The instrument in this study is WeeFIM (The Functional Independence Measure for Children). Respondent criteria: mild-severe degree of intellectual disability based on the Mental Retardation Screening examination, ID child's parents are willing and committed to following research procedures, ID child's parents are able to read and can understand the contents of the module (minimum junior high school graduates).*

Results: *Mean value after intervention = 103.21 (> mean before intervention = 96.54) and statistically significant (p = 0.000). It showed that family empowerment (training and monitored home programs) significantly increased the independence of children with intellectual disabilities.*

Conclusion: *The family empowerment program (training and monitored home programs) is a cheap, easy, and effective program for ID children, and it can be applied to all families of ID children.*

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CONTACT
Linda Harumi
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lindaharumiot@gmail.com
Department of Occupational Therapy, Poltekkes Kemenkes Surakarta. Jl. Adi Sumarmo, Merten, Tohudan, Kec. Colomadu, Kabupaten Karanganyar, Indonesia 57173.

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INTRODUCTION

Intellectual Disabilities (ID) are one of the most common mental disability problems, with a general population prevalence of ID in the world across all 52 studies from 1980 until 2009 included in the meta-analysis of 10,37/1000 population (Maulik et

al., 2011). ID is a developmental disorder characterized by a lack of intellectual and adaptive functioning in conceptual, social, and practical domains (American Association on Intellectual and Developmental Disabilities, 2023). American Psychiatric Association, (2015) conveys three main problems in the adaptive functioning of ID children, namely in three domains: conceptual, social, and practical.

In the conceptual domain, children have difficulty with memory, language, reading, writing, mathematical reasoning, understanding practical knowledge, problem solving, and observing new situations. In the social realm, it causes children difficulties in empathy, interpersonal communication skills, the ability to make friends, and other social assessments. Whereas in the real world, the problems of ID children are learning and self-management in various aspects of life, including personal care, job responsibility, money management, leisure activities, self-management of behavior, school learning, and organization of other work tasks.

The adaptive function of ID children is influenced by their intellectual capacity, level of education, motivation, socialization, personality, employment opportunities, cultural experience, and general medical conditions or mental disorders (American Psychiatric Association, 2015). The maladaptive behavior of ID children in 3 domains causes children to be incompetent in social skills: interpersonal skills, social responsibility, self-esteem, being easily deceived and naive, difficulty solving social problems, and difficulty following society's rules and obeying the law. Conceptual skills: understanding time, money management, and language.

Practical skills include using tools, performing activities of daily living, and interacting with others (Lee et al., 2019). It is a crucial issue that must be addressed, because if this is not handled, then the problem that occurs later is that the ID child will become a burden on the family or caregivers until adulthood. Thomas et al., (2019) conducted research and came to the conclusion that ID requires the role of the family in handling it throughout the life span. ID requires independent mobility training, physical care, communication needs, education modified according to the child's abilities, assistance and equipment, employment and vocational opportunities, and medication if needed.

Therefore, holistic programs must meet lifelong needs gradually. ID children are in their preschool years and need to be trained in self-care, social communication skills, and school readiness skills. School-age ID children and adolescents need educational treatment and preparation for work and an independent life in the future. When there is no longer a family or caregiver to care for them in the future, children are unable to care for themselves and are neglected. In addition, children who are not independent in their ADLs will become insecure and find it difficult to be accepted by the social environment.

Providing ADL independence training for ID children is very important. One of the obstacles to giving ID children independence training is the lack of knowledge and skills of ID families and caregivers in handling ID and how to train independence in ID children. Families of ID children, especially in areas that are quite far from urban areas, mostly still have difficulty accessing information about handling ID through various media, such as books, the internet, videos, consultations with doctors and therapists, and limited opportunities to attend training and workshops on ID.

There are still many parents of ID children who do not realize that the main role in handling ID children is the family. Families know the needs, abilities, and daily ADL habits of children best, and children spend more time with their families than they do at

school. Almost all families did not receive adequate formal information about ID from health professionals after their child's diagnosis, so families lack basic knowledge about the diagnosis and management of the behavior and overall development of their children with ID. Families have demonstrated the importance of information to understand the care needed to improve the quality of life of their family members (Modula, 2022).

Solutions for handling ID children's ADL independence can be implemented according to policy. Peraturan Menteri Negara Pemberdayaan Perempuan Dan Perlindungan Anak, (2011) Concerning Handling of Children with Special Needs, with a family and community empowerment strategy based on fulfilling children's rights. Indicators of family empowerment based on these regulations are increasing the understanding and skills of parents, families, and communities in handling children with special needs.

To face these challenges, a guidebook or guideline for the implementation of the home program is needed, and monitoring is in the form of a record of evidence of the implementation of the home program (Brumbach and Louthain, 2015). The home program is a component of occupational therapy services that can be used to achieve therapeutic goals so that the patient's abilities improve. Harumi, (2017) shows an increase in the empowerment (knowledge, attitudes, and empowerment) of families with CP children after providing practical integrative modules for CP handling that support the process of handling CP children. The results of this research inspired this research, with the hope that ID children can grow and develop.

MATERIALS AND METHOD

This research was conducted using a quasi-experimental method with a one group pre- and post-test design to compare before and after the intervention. The research location was at Boyolali SLBN from July to August 2022. The sample in this study was 28 ID children who were selected through a purposive sampling technique. ADL independence in ID children was measured before and after the intervention using measurement instruments for functional independence (ADL).

This questionnaire can be used for normal children aged 6 months to 7 years or children with developmental disorders aged 6 months to 21 years. WeeFIM consists of 18 items, with an item score of 1–7. The three domains that WeeFIM measures are self-care, mobility, and cognitive. Performance assessment is carried out through interviews or direct observation of children's performance.

FIM assessment: "dependent": score 1–5, and "independent": score 6-7. Scores of 1 (total assistance) and 2 (maximum assistance) fall into the "full dependency" category. Score 3 (moderate assistance), 4 (minimum assistance), and 5 (supervision or direction, including needing assistance with modifications). Scores 6 (modified independent) and 7 (full independent). Data analysis with the Paired Samples T-test.

RESULTS

Table 1 shows the results of descriptive statistics on the characteristics of research subjects from 28 samples with the most male sex, namely 20 children (71.4%), the majority of ID children in the moderate category were 13 children (46.4%), and the majority of the sample is 10–12 years old with an average age of 10.75 years. The average increase in ADL independence for ID children before the intervention (96.54) and after the intervention (103.21) was a difference of 6.68.

Characteristics of categorical data research subjects

Table 1. Characteristics of Categorical Data Subjects (n = 28)

Variable	f	%
Gender		
Man	20	71.4
Woman	8	28,6
Severity Level		
Light	7	25.0
Currently	13	46,4
Heavy	8	28,6

Characteristics of continuous data research subjects à add explanation result of this table

Table 2. Characteristics of Continuous Data Subjects (n = 28)

Variable	Means	SD	Min.	Max.
Age	10.75	2.35	7.00	16.00
Pretest ADL Independence	96.54	12.92	73.00	119.00
Posttest ADL Independence	103,21	11.74	76.00	121.00

It shows that the average age of the subjects is 10.75, which belongs to the child age category. There was an average increase in the independence of ID children before the intervention (96.54) and after the intervention (103.21), which was 6.68.

The Effectiveness of Family Empowerment (Training and Monitored Home Programs) in Increasing the Independence of Children with Intellectual Disabilities at Boyolali SLBN.

The results of the data normality test using the Shapiro-Wilk test showed that the independent variable ADL before and after treatment was normally distributed ($p > 0.05$). So the statistical test used is the paired sample t-test.

Table 3. Paired Samples T-test (n = 28)

Variable	Means	t	p-value
Pretest ADL Independence	96.54	-12,053	0.000
Posttest ADL Independence	103,21		

The results of the Paired Samples T-test showed that interventions (training and monitored home programs) proved effective in increasing children's independence and were statistically significant ($t = -12.053$ and p value 0.000 (<0.05).

DISCUSSION

Research with the title Family Empowerment Through Monitoring Modules and Home Programs proved effective and statistically significant ($t = -12.053$ and p value 0.000 (<0.05) to increase ADL independence in ID children. This means that they are more empowered (with increased knowledge, attitudes, and skills) parents in handling ID children, and they are more optimal in training ADL independence in ID children. The results in India also corroborate the results of this study, which show that training and education programs for caregivers for early intervention in children with

developmental delays show positive changes in reducing caregiver tension and increasing family empowerment (Muthukaruppan et al., 2013).

Family education is an essential service provided by healthcare providers for family members of intellectually disabled patients. The first part of this is assisting the family members in understanding intellectual disability: definition, management, and prognosis. Then, healthcare providers can help the family through placement decisions, refer them to appropriate services and equipment, and provide caregiver training (Lee et al., 2019). The results of this study are also supported by research from Susilowati, (2020) which states that parental involvement in formal programs, children's programs, training involvement, and agency involvement carried out by parents is generally in a fairly high category.

ID children have intelligence barriers, so the independence training provided must be adjusted to their potential. This requires comprehensive treatment between parents, psychologists (counselors), psychiatrists, teachers, and therapists. In education, the handling of ID children needs to be emphasized, along with the development of social skills and simple self-development activities to achieve independence (Kirana et al., 2018).

Families lack information on handling ID children, so it is necessary to provide information on various aspects related to parenting ID children, behavior management, as well as information about children's rights. In addition, it is very important to equip families with the knowledge to train, care for, and support their children in learning self-care and basic cognitive skills. Lack of knowledge is a barrier for families to plan special care for their children with ID (Davys et al., 2010). Parents also need to gain knowledge to reduce stress, adapt to the child's condition, and be able to do proper parenting for children ID in the home environment (Douglas et al., 2017).

Empowerment is a process of providing information and assistance to individuals, families, or groups (clients) to deal with health problems on an ongoing basis, as well as a process of change so that the client changes from not knowing to knowing or being aware (knowledge aspect), from knowing to being willing (attitude aspect), and from wanting to be able to carry out the expected behavior (Menteri Kesehatan Republik Indonesia, 2013). Duma et al., (2021) recommend professional education and training programs for families. This is useful for increasing family empowerment (knowledge, attitudes, behavior, and skills) to support and encourage families to actively participate in the care of their children with ID (Caldwell et al. 2018).

Modula, (2022) which states that every family of ID children has various, complex, and unique problems. Therefore, an approach that involves various parties to address problems and improve the quality of family life, namely by involving stakeholders representing various sectors, organizations, and services. In this study, collaborative empowerment was carried out by occupational therapists and schools using the media module and the home program method. In the future, it is hoped that there will be many programs to increase the empowerment of ID children's families by various parties, using various empowerment methods and techniques that are suitable for each population.

Parents who receive training have a more empathetic attitude and have an impact on their children's progress (Burton et al., 2018). Mother training programs are effective for both mothers and children and have positive outcomes for children with special needs (Bayrakli & Sucuoglu, 2018). Setiawati et al., (2021) prove that there is a relationship between the role of the family as a provider of equipment and materials, as

a caregiver, nurse, and socialization platform for children with special needs and children's ADL independence. There is a significant relationship between parents' education, age, and motoric strength in mentally retarded children with abilities (Ramawati et al., 2012).

CONCLUSION

The family empowerment program (providing modules and monitored home programs) has proven to be effective in increasing the independence of ID children. The more empowered parents are (in knowledge, attitudes, and skills) in handling ID children, the more optimal they are in training ID children's ADL independence. Early intervention for ID children has shown positive results in reducing caregiver stress and increasing family empowerment.

ID children's independence training must be adjusted to their potential, and what needs to be prioritized is the development of social skills and self-development activities (ADL). Required an approach that involves various parties for programs to increase the empowerment of ID children's families so that families are empowered, ID children are handled properly, and ID children become independent so that the quality of life of families and ID children can improve. Programs to increase the empowerment of ID children's families need to be carried out by various parties, using a variety of empowerment methods and techniques that are appropriate for each population.

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REFERENCES

American Association on Intellectual and Developmental Disabilities. *(2023). Defining Criteria For Intellectual Disability.* https://www.aaidd.org/intellectual-disability/definition

American Psychiatric Association. (2015). *Diagnostic And Statistical Manual Of Mental Disorders DSM-5 TM*. www.psychologymania.com

Bayrakli, H., & Sucuoglu, B. (2018). Empowering mothers of children with special needs in early childhood inclusion. *International Journal of Early Childhood Special Education*, *10*(2), 121–143. https://doi.org/10.20489/INTJECSE.512387

Burton, R. S., Zwahr-Castro, J., Magrane, C. L., Hernandez, H., Farley, L. G., & Amodei, N. (2018). The Nurturing Program: An Intervention for Parents of Children with Special Needs. *Journal of Child and Family Studies*, *27*(4), 1137–1149. https://doi.org/10.1007/s10826-017-0966-3

Casey Brumbach and Kathryn Louthain. (2015). *Running head: ACTIVITIES-BASED HOME PROGRAM MANUAL An Activities-Based Home Program Manual for Student Occupational Therapists in a Campus-Based Teaching Clinic*.

https://soundideas.pugetsound.edu/cgi/viewcontent.cgi?article=1105&context=ms_occ_therapy

Davys, D., Mitchell, D., & Haigh, C. (2010). Futures planning, parental expectations and sibling concern for people who have a learning disability. *Journal of Intellectual Disabilities*, *14*(3), 167–183. https://doi.org/10.1177/1744629510385625

Douglas, T., Redley, B., & Ottmann, G. (2017). The need to know: The information needs of parents of infants with an intellectual disability—a qualitative study. *Journal of Advanced Nursing*, *73*(11), 2600–2608. https://doi.org/10.1111/jan.13321

Duma, V. V., Tshabalala, N., & Mji, G. (2021). The black hole of dealing with a disability diagnosis: Views of South African rural parents. *African Journal of Disability*, *10*. https://doi.org/10.4102/AJOD.V10I0.951

Kirana, A., Fakultas, A., Universitas, P., & Buana, M. (2018). Dukungan Sosial Guru Dalam Upaya Membimbing Kemandirian Anak Moderate Intellectual Disability. In *Provitae Jurnal Psikologi Pendidikan* (Vol. 11, Issue 2).

Lee, K., Cascella, M., & Marwaha, R. (n.d.). *Intellectual Disability Continuing Education Activity*.

Harumi, L. (2017). *Efektivitas Modul Integratif Praktis Dalam Pemberdayaan Keluarga Dengan Anak Cerebral Palsy Tesis.*

Maulik, P. K., Mascarenhas, M. N., Mathers, C. D., Dua, T., & Saxena, S. (2011). Prevalence of intellectual disability: A meta-analysis of population-based studies. In *Research in Developmental Disabilities* (Vol. 32, Issue 2, pp. 419–436). https://doi.org/10.1016/j.ridd.2010.12.018

Modula, M. J. (2022). The support needs of families raising children with intellectual disability. *African Journal of Disability*, *11*. https://doi.org/10.4102/AJOD.V11I0.952

Muthukaruppan, S., Eswari, A., & Rajendran, L. (2013). Mathematical modelling of a biofilm: The Adomian decomposition method. *Natural Science*, *05*(04), 456–462. https://doi.org/10.4236/ns.2013.54059

Menteri Kesehatan Republik Indonesia, (2013). *Peraturan Menteri Kesehatan Republik Indonesia Nomor 65 Tahun 2013 Tentang Pedoman Pelaksanaan Dan Pembinaan Pemberdayaan Masyarakat Bidang Kesehatan*. Kementerian Kesehatan Republik Indonesia. https://peraturan.bpk.go.id/Home/Details/129749/permenkes-no-65-tahun-2013

Menteri Negara Pemberdayaan Perempuan dan Perlindungan Anak. (2011). Peraturan Menteri Negara Pemberdayaan Perempuan dan Perlindungan Anak No. 10 Tahun 2011 tentang Kebijakan Penanganan Anak Berkebutuhan Khusus.

(2011). *Menteri Negara Pemberdayaan Perempuan Dan Perlindungan Anak* . https://peraturan.bpk.go.id/Home/Details/129749/permenkes-no-65-tahun-2013

Ramawati, D., Allenidekania, A., & Besral, B. (2012). Kemampuan Perawatan Diri Anak Tuna Grahita Berdasarkan Faktor Eksternal dan Internal Anak. *Jurnal Keperawatan Indonesia*, *15*(2), 89–96. https://doi.org/10.7454/jki.v15i2.32

Setiawati, R., Sunardi, S., & Yuwono, J. (2021). Parental support for independence of children with special needs in distance learning. *International Conference on Special Education In South East Asia Region 11 Th Series*, *8*, 2021. https://doi.org/10.32698/GCS-11516

Susilowati. (2020). *Keterlibatan Orang Tua Dalam Kemampuan Bantu Diri Anak Tunagrahita*. http://lib.unnes.ac.id/42983/1/1511414041%20-%20dwi%20susilowati.pdf

Thomas, M. K., Udipi, G. A., & Seshadri, S. P. (2019). Clinical practice guidelines for assessment and management of intellectual disability. In *Indian Journal of Psychiatry* (Vol. 61, Issue 8, pp. S194–S210). Wolters Kluwer Medknow Publications. https://doi.org/10.4103/psychiatry.IndianJPsychiatry_507_18