September 30, 2024

Dear Professor Rafat Hussain, Editor-in-Chief,

Journal of Intellectual & Developmental Disability (JIDD)

Re: Submission of Revised Manuscript ID-2024-0078

We would like to express our appreciation to the reviewers for their thorough and constructive critiques of our manuscript titled "Parents' Initiative in Community-Based Support for Children with Intellectual and Developmental Disabilities: The Ahada Non-Profit Model". Their insightful feedback has been instrumental in enhancing the quality of our research.

In accordance with the reviewers' comments, we focused the Introduction and the first chapter on the processes with which parents cope when their children with IDD transition from infancy to adulthood. Following that, we updated parts that referred to comparative and critical aspects of the *Ahada* model in the chapter explaining *Ahada* and in the Discussion. In addition, we corrected the Methods chapter according to reviewers’ comments and updated terminology. We also deleted large parts of the original text, especially in the introductory and theoretical chapters, in order not to exceed the word limit.

As suggested by the reviewers, we updated some of the references and included them in the Discussion.

In the table below, in accordance with the journal guidelines, we made sure that the response was as detailed as possible and easy to find in the text of the article (on a gray background).

We would like once again to thank the reviewers for constructive comments which we believe have contributed to the focus and improvement of the article.

Thank you for your consideration of our revised manuscript.

Sincerely,

The Authors

Here are our answers to the reviewer comments in the table. For facilitate finding the updates/changes:

Reviewer: 1

Thank you, for your valuable detailed feedback.

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| Comments to the Author - Overall Impression | Our responses |
| Please include information about type of interviews you conducted and the approach to data analysis in the abstract. | Thank you for your suggestion. We have revised the abstract to include information about the interview type and data analysis approach. Specifically, we have added: " In-depth interviews were conducted with 12 participants and used a thematic analysis based on case study methodology.” |
| I suggest you review the language you use when referring to people with intellectual and developmental disabilities and avoid highly medicalized terms such as 'disorder', which are largely rejected by the neurodivergent community. I would also suggest to change terms like 'psychopathology' and 'academic underachievement' (page 8). | Following your important comments, we changed several terms throughout, from  Integration to inclusion  Disorder to Disability  We also, avoided terms like 'psychopathology' and 'academic underachievement' . |
| Please explain why views of people with intellectual and developmental disabilities were not sought in this study. | Thank you for raising this important point. We recognize this as a limitation of our study, and now cite that point in the Limitations section. |
| Please described the relationship (if any) of the interviewer to the kibbutz communities. | The authors are part of the intentional community although they do not have family members with IDD. We have added a comment in the Ethics section of the Methods. |
| You mention that follow-up interviews were conducted in 2022 (page 12), but no other information is supplied. Please explain what was the purpose of the follow-up interviews, if they followed the same questions, if all participants were followed up on, and how data from follow-up interviews were integrated with the original sample. | Thank you for this question. The follow-up interviews in 2022 provided another opportunity to verify the integrity of the data after the Covid-19 period and to answer questions about processes that may have occurred in the model over time. Since there was no change in the model and the corona did not affect practices for its implementation, the supplement added in the later interviews was integrated and gave an updated picture of the families and their parents.  We added an explanation in the Methods section. |
| Please include short sentence in the method section explaining how the interviews were transcribed. | In the Methods section, it was noted that the interviews were recorded on Zoom, their transcripts were analyzed using the method of codes according to the research question and research topics and the theory and codes were analyzed to first-order and second-order thematic groups until saturation. The interview transcripts were read several times, and the main codes that emerged were marked, according to the methodology of Charmaz and Thornberg (2021)." |
| A thematic map or a similar figure would be a helpful addition to the results section. | Thank you for your helpful suggestion. Although we did not add a thematic figure, we have refined the wording in the Results chapter so that they allow a processive understanding of the findings and what emerges from them |
| I'm concerned about the confidentiality given that participants will be named in the paper. Please explain how you ensured that participants understood the implications of being named in the paper and the risks to confidentiality of their data. | We appreciated your concern about participant confidentiality and have changed to pseudonyms to protect their privacy. There is an explanation of this in the Ethics section in the Methods chapter. |
| **Suggested minor edits:** - P2 line 20 - delete extra semicolon - P2 line 30 - delete 'these' - P9 lines 34-38 - this sentence is not clear - P21 line 40 - delete extra 'that' | Done |

Reviewer: 2

Thank you for your detailed comments. We have reviewed and made corrections accordingly, including adjustments in phrasing and terminology, along with other remarks. Detailed changes are presented in the attached table:

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| Comments to the Author - Overall Impression | Our responses |
| **Introduction** There is already considerable literature on the various models of providing supports to people with disabilities, so I would suggest the authors to significantly reduce the section entitled Approaches to the treatment of people with intellectual and developmental disorders in the community. For example, I believe that explaining the difference between inclusion and integration is no longer necessary considering the readership of this journal. | Thank you for the helpful suggestion. Accordingly, we significantly shortened the section on approaches to support people with IDDs and focused on the literature dealing with models in the community specifically relevant to the *Ahada* model and the unique context of the kibbutz. |
| I would also recommend reviewing the terms used when referring to individuals with IDD. The term ‘intellectual and developmental’ disorders reflects a medical rehabilitation model with which I am not sure the authors identify themselves. | Thank you for this important comment. We have updated our terminology throughout to reflect a more respectful and less medical approach. The term ‘individuals with IDD’ now appears throughout the article, which places the person in the center. We also replaced Disorder with Disability |
| In page 6 the authors stated that ‘it is easier for people with intellectual and developmental disorders to build personal security and social connections in a small community’ and this statement seems to be used as an argument to support the Ahada model (or similar ones) above others. Such statements seem to suggest that people with IDD are the ones who must 'find' an ‘easy’ place to live and fit in the community, when it should be the other way around. | Thank you for bringing this important point to our attention. We agree that the original wording could be interpreted in a problematic way. We changed the text as follows: Melucci (1996) found that a community’s collective action can provide a supportive environment that promotes social relationships and a sense of security for all its members, including those with IDD.  This wording reflects a more inclusive approach, together with the preliminary sentences about studies that found that a community benefits from diverse people within it and offers a broad picture of the benefits of inclusion. |
| As the authors described, eligibility to join Ahada is based on several criteria that include the requirement of parental membership in a kibbutz and the signing of the Ahada agreement. First, the requirement for parents to belong to the kibbutz suggests a certain segregationist nature of the model, since not all people who might require some type of support, whether or not they have a disability, can access this service. Second, the agreement outlines a course for the kibbutz to take overall responsibility for all the needs of the person with intellectual and developmental disorders and offers him/her a place to live for life in the IC within the kibbutz. In return, the parents agree to give up their children's future rights to membership in the kibbutz, effectively excluding them from the decision-making processes. It is very likely that I am misunderstanding the implications of this model, but the description made leads me to wonder: Where is the respect for the rights of the individual with disability and his or her status as a citizen in a model that, in some way, hands over to a third party the course of his or her future? Why is it that in this model, the fact that a community offers supports to a person with a disability is incompatible with parents maintaining any rights they may have over their children? To what extent does a kibbutz allow people to enjoy the right to choose where, how and with whom to live as enshrined in Article 19 of the Convention on the Rights of Persons with Disabilities? | Thank you for raising these important questions. The advantages as well as the limitations of the *Ahada* model emerge from its description, from the interviewees’ comments, and mostly from the Discussion, and so these criticisms need evaluation for updating and change.  To your question, the research framework focuses on kibbutzim, people with disabilities who grew up in kibbutzim which are typically situated in the country’s periphery, far from city centers. For example, after the death of his parents, Avraham chose to split from *Ahada* and send his sister to a more distant government institution far from the kibbutz, due to the costs of *Ahada*.  We added a paragraph to the Discussion that clarifies the weaknesses of the model for kibbutz members and in general, and we referenced Article 19 of the Convention on the  Rights of Persons with Disabilities (Kanter, 2017) |
| **Research Design** Is there any other model of supports for people with disabilities in a kibbutz? If so, Why the Ahada model was chosen for analysis? | Thank you for your question. We have added an explanation that the *Ahada* model is the most common and well-established model for supporting people with disabilities in kibbutzim, so we focused on it. Other models that exist in Israel are mentioned in the literature review and in the Results chapter - in Ron's comments in the third theme and again in the discussion. |
| **Methods** How were codes and categories obtained? Was there more than one researcher involved in the analysis to avoid bias when coding and identifying categories? Themes seem quite broad and general, so I was wondering if no different themes or subthemes emerged when coding. | Thank you. We expanded the section on data analysis to include more details about the coding and the fact that it was done by two researchers, independently of one another. |
| Are 12 interviews sufficient to achieve data saturation? | Thank you for this important question. We added an explanation in the Methods section:  " The small number of study participants did not prevent the wealth of information that reached saturation as stipulated by Young and Casey (2018)." |
| The authors stated that they used a questionnaire to conduct the interviews, which seems contrary to a case study approach (also mentioned). Could the authors explain why using a questionnaire was deemed necessary and how this might complement a case study approach? More detail on how the questionnaire was developed would be appreciated. | Thank you for asking us to clarify this point. The use of the word ‘questionnaire’ was misleading. We changed it to ‘semi-structured interview guideline’, and we added an explanation and a link to the case study approach. |
| The authors say that Semi-structured interviews that aim to uncover the experiences and perceptions of the interviewees in an in-depth and detailed manner (Creswell & Poth, 2016) were conducted via Zoom in March-June 2020, with follow-up interviews in July-August 2022. What is the purpose behind conducting interviews at two different time points when differences in perspectives over time are not analyzed? | Thank you for your question; an explanation has been added in the data collection subsection. In that section, we expanded on our repeated request of the interviewees for up-to-date information, especially for the duration of the Covid-19 period. |
| **Results** Why perspectives of individuals with intellectual and developmental disabilities were not collected? This limitation requires further discussion, since how individuals will receive supports in a future is what is being under study. | We agree that this is a limitation that could not be addressed in this study. Therefore, we added the topic to our expectations for future research where the voices of people with IDDs can be included |
| **Discussion** It seems that the downsides of the model are not discussed, while some of them were even addressed by some interviewees. | Thank you for this important insight. We have added the challenges and disadvantages of the model in the discussion chapter. |
| Do concerns of these parents differ from those of other parents of children with IDD? | Thank you. We have added a reference to this in the discussion. Additionally, in the study limitations, we added that future comparative research between parents in kibbutzim and parents in other settings could provide further insights on this topic. |

Reviewer: 3

Reviewer’s remarks

Thank you for your detailed comments. We have reviewed and made corrections accordingly, including adjustments in phrasing and terminology, along with other remarks. Detailed changes are presented in the attached table:

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| --- | --- |
| Comments to the Author - Overall Impression | Our responses |
| Further context of the method within the abstract would be beneficial to an audience | Thank you for your suggestion. We have revised the abstract to include information about the interview type and data analysis approach. |
| Within the Review of Literature, it is important to provide further evidence and context relating to regional understanding. For example, statements relating to difficulties associated with transitions from childhood to adulthood could be discussed in relation to localised or international perspectives and then linked to the focus of the article more explicitly. | Thank you for this helpful comment. We expanded the introductory and literature review chapters to include regional and international context. For example, we added a comment about the challenges for a family when the person with IDDs transitions from childhood to adulthood in Israel compared to other countries, which makes the research more accurate and relevant.  This expansion is in the subsection: |
| Discussion on models of disability need to be localised to the geographic region it relates as not all localities have moved beyond a medicalised approach to disability. This explicit information is needed to address the social environment at the basis of the research. | Thank you for your comment. We have added specific information on the approach to disabilities in Israel, including reference to relevant legislation and current trends. We highlighted how the medical model still influences certain aspects of policy and services, alongside progress towards more social models. As for the regional variation, the kibbutzim are in the geographical periphery of Israel and therefore its members need to find local solutions. Also, for members of kibbutzim in the process of organizational change, the relevance of the model is explained. In kibbutzim that have not been privatized (some do exist) - the model of *Ahada* provides a response to the time when change will come (since the trend of change exists). The model meets the concerns of parents even if currently the kibbutz meets all the needs of its members and their families. The situation will most likely change and they will need to decide how to prepare for that day. |
| P. 9 Line. 42: amend ‘him’ to ‘them’ | Amended. We went through the manuscript to change the language to gender-neutral. |
| P. 10 Line. 8: Reframe ‘In conclusion, the literature review…’ to be more consistent with an article format, not a thesis. | Amended. Thank you. |
| The section on data analysis requires a more detailed overview of who participated in the coding and how inter-rater reliability was ascertained. | Thank you. In the Methods section we expanded the section on data analysis to include more detailed information. |
| The ‘First Theme’ appears more concerned with support requirements rather than the immediate or ongoing changes that occur after the birth of a child with an intellectual or developmental disorder. | Thank you. In response to your comment we re-edited the 1st theme so as to emphasize the immediate and continued changes experienced by the parents. We rewrote the theme’s title as:First theme: A family’s life changes after the birth of a child with intellectual and developmental disabilities We also reorganized the content to reflect this point. |
| Ilana’s voice is very prominent within the results. Additional quotations from other participants would be beneficial to establish the generalizability of themes within the results across participants. | Thank you. For more balance among the participants’ voices we added a greater variety of quotes to demonstrate the themes we identified.  Note: Ilana's name was changed to Lea and all other names were changed except for the employees, following the comment requesting to reconsider the anonymity of the participants. |
| Clarifying the role of each participant (e.g., parent, sibling, etc.) after their name would be helpful to view the perspective shared: e.g., …Ilana (parent)… | Thank you for your helpful suggestion. We implemented your recommendation and added an identifier (parent, brother…) for each interviewee comment we quoted. |
| The discussion provides commentary on the author’s findings, but requires a more detailed analysis of how the results fit within the current body of knowledge on raising children with disability, community supports, etc. It would be helpful to provide more details around the supports offered to families of and individuals with intellectual and developmental disabilities in Israel that do not live within a kibbutz. This would provide an opportunity to compare and contrast the results across the three themes with those not involved in Adaha or similar intentional communities. | Thank you for this comment. We added information about other models in the interviewees’ comments in the Results section. In the Discussion we added a more detailed analysis of how our findings integrate with what is already known in the field. |
| **General Comments** Make sure to maintain a consistent tense: past and present tenses are used interchangeably throughout. | We reread our manuscript and changed the verbs so that the tense is consistent, generally using the past tense for methods and results, and present tense for discussion and conclusions. |
| Review the use of ‘integration’ throughout to ensure the accuracy of the term used in the context of the research. | Thank you. We replaced integration with inclusion to explain ourselves more precisely and to reflect our understanding of current attitudes in this area in general, in this model and in our own approach. |

Once again, we appreciate the help of the editors and the three anonymous reviewers in helping us to upgrade our manuscript.

The authors