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Supporting the mental health of mothers of children with a disability: health professional perceptions of need, role, and challenges.

Short title: Health professionals supporting mothers

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Conflict of Interest

The authors have stated that they had no interests that could be perceived as posing a conflict or bias.

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Abstract

Background – Mothers of children with a disability have a higher risk of mental health difficulties than mothers of typically developing children. Very little is known about how health professionals perceive their role in supporting mothers' mental health. We aimed to explore the perspectives of health professionals working with families of children with a disability about how they provide support for maternal mental health in their roles. Specifically, whether professionals consider it their role and responsibility to provide support, the types of actions that they engage in to do this and the challenges that they experience.

Methods – This qualitative semi-structured interview study included 13 health professionals (allied health professionals, general practitioners and paediatricians) working with families of a child with a disability. Thematic analysis was conducted on transcribed interview data.

Results – Four overlapping themes were identified from the data indicating that professionals knew that mothers needed mental health support but were not always clear about their roles and responsibilities to support maternal mental health. Professionals also found it difficult to address maternal mental health difficulties, were not always aware of the best strategies to support maternal mental health and faced difficulties that could be overcome with training and system improvements.

Conclusions – Although all health professionals were aware of the frequent occurrence of maternal mental health difficulties and the importance of addressing them, several challenges were identified to managing them successfully. Providing health professionals with training in discussing mental health and clearer referral pathways would contribute to mothers being better supported, in addition to policy change that allows parental support in child health services.

Key messages

Health professionals have a good understanding of the mental health difficulties faced by mothers of children with a disability.

Health professionals who provide care to children with disabilities take on various roles in facilitating their access to support.

Health professionals, particularly in allied health roles, may lack the confidence and skills to provide support to mothers for their mental health despite feeling well positioned in their role to do this.

There is a need for increased professional development and training to build the capacity of health professionals to support mothers' mental health.

Introduction

Parents of children with a disability experience exceptional challenges that are daily, lifelong and impact all areas of their lives, including their physical and mental health, employment, finances, and relationships. Parents, particularly mothers, of children with a disability are more likely to experience mental health difficulties than mothers of typically developing children (Davis & Carter, 2008; Resch, Benz, & Elliot, 2012; Sharpley, Bitsika, & Efremidis, 1997; Singer, 2006). In a recent study of 300 Australian mothers of children with a disability, almost half had clinically significant depression (44%) and anxiety (42%), compared with 5% and 15% respectively of the general population of females (Gilson et al. 2018). These authors also found that a significant gap existed between those who perceived a need for professional mental health support and those who had actually accessed this support (Gilson et al., 2018).

Strategies for early detection and treatment of mental health difficulties are urgently needed for mothers of children with a disability. Without treatment, mental health difficulties have the potential to reduce the quality of care provided to children with disabilities and their siblings (Murphy, Christian, Caplin, & Young, 2006; Stein, Belik, Jacobi & Sareen, 2008). Bourke-Taylor, Howie and Law (2010) found that a significant proportion of mothers with school-aged children with a disability felt their health affected their ability to provide the care their child needs. It is well established that depressive symptoms in mothers have serious negative consequences for children, with mothers feeling less attached to, and more negatively, toward their children (Lovejoy, Graczyk, O'Hare & Neuman, 2000; Murray, Halligan, & Cooper, 2010; Wan & Green, 2009).

Mothers of children with a disability frequently visit their child's health professionals including their child's paediatrician, general practitioner, and allied health professionals (physiotherapists, speech pathologists, occupational therapists, and psychologists). One opportunity for intervening early with maternal mental health difficulties would be for child health professionals to routinely monitor and discuss mothers' mental health. Mothers have reported this to be particularly important at key points such as at their child's diagnosis, and during key developmental changes (Gilson et al., 2018). Supporting the mental health of mothers of children with a disability also aligns with the growing orientation towards family-centred practice as standard care (Law & Teplicky, 2005). Although this does not explicitly address maternal mental health, it recognises the importance of family wellbeing to child wellbeing (Rosenbaum, S. King, Law, G. King & Evans, 1998).

Although little is known about how health professionals working with families of children with disabilities provide support for mothers' mental health, previous studies on mental health in the peri- and postpartum period provide insight. Researchers in the US have advocated for paediatricians to engage in maternal mental health screening and to discuss family stress (Heneghan, Morton & DeLeone, 2007). This body of literature highlights multiple barriers to paediatricians enquiring about maternal mental health such as inadequate training, lack of time, perceived low quality of community mental health services, and perceptions that mothers are in denial (Byatt et al., 2012; Chew-Graham, Sharp,

Chamberlain, Folkes & Turner, 2009). Other research with paediatricians and other health professionals found that significant barriers included lacking confidence in introducing the issue of mental health, and fear of mothers feeling stigmatized (Agapidaki et al. 2014).

In the context of disability, Early Childhood Intervention Services (ECIS) provide specialised support and services for young children with disability and/or development delay and their families to promote development, wellbeing and community participation. Allied health professionals within ECIS work in close partnership with families, helping enhance their knowledge, skills and supports to care for their child while taking a holistic care approach to the family. Given this close relationship with families, these professionals may be well placed to address mothers' mental health. However, no research to date has addressed this. Furthermore, there is no current documentation or guidelines that explicitly refer to responding to mothers' mental health difficulties. Key best practices in Early Childhood Intervention (National Guidelines for Best Practice in Early Childhood Intervention, 2016) recommend allied health professionals address risk factors, such as parent mental health, that can undermine parents' abilities to address their child's needs. However, it is left to professionals' own judgement to identify strategies to suit the parent, within a family-centred and strengths-based approach.

We aimed to explore the perspectives of various health professionals working with families of children with a disability on how they provide support for maternal mental health. Specifically, we explored whether professionals consider it their role and responsibility to provide support, the types of actions they engage in to do this, and the challenges that they experience. These findings will inform future research and interventions to improve early detection of mental health difficulties and facilitate pathways of health professional support for mother's mental health.

Method

Given our research was exploratory, we utilised a qualitative approach with semi-structured interviews. The study was approved by the University of Melbourne, Australia ethics review committee (HREC 1543687.3). Written informed consent was obtained from all participants. A parent and carer engagement group from the University of Melbourne, which includes six mothers who guide and provide advice about research, met to inform the recruitment strategy and interview schedule.

Participants and recruitment.

Thirteen health professionals responsible for delivering care to families of children with a disability within Victoria, Australia completed interviews. Participants included eight allied health professionals, three paediatricians, and two general practitioners (GPs), ensuring a variety of professional disciplines and service settings. This was important given the broad range of health professionals who see families of children with a disability and to explore differences in how these professionals support mothers' mental health.

Allied health professionals included one speech pathologist, one social worker, three occupational therapists, one physiotherapist and two psychologists. Six of the allied health professionals worked within Victorian ECIS where they were the primary contact for the family, connecting them to a range of community supports in addition to child therapy. They visited families once a fortnight in the family home focusing on children aged 0 to 6 years with disability and/or developmental delay. One allied health professional was hospital based and another worked in a group private practice. The two GPs were from general community practices and three paediatricians were from hospital settings. These health professionals, especially medical professionals and allied health staff in ECIS, would have contact with mothers of children with all types of developmental difference and disabilities. Health professionals were aged 25-45 years, with 5-20 years of experience working with families of children with disabilities. Allied health professionals and GPs were female; paediatricians were two males and one female. One health professional was located in rural Victoria and all others were metropolitan-based.

Purposive sampling was used with professionals selected for their knowledge and expertise in working with families of children with a disability aged 0-25 years. These professionals were identified by the research team and parent engagement group who provided advice based on their experience of health professionals they see for their child.

Interviews.

The semi-structured interview schedule used broad open-ended questions. These were developed with the parent and carer engagement group and varied minimally during the initial interviews. Examples of questions included '*Can you tell me about your role working with families who have a child with a disability?*', '*How do you support mothers' mental health in your current role*', '*What makes it challenging for you to support mothers' mental health?*', and '*Who do you think is best suited to be discussing mental health with mothers?*'.

A trained interviewer conducted and audio-recorded each interview after obtaining verbal consent. Ten interviews took place at participants' workplaces and three were conducted by phone. Interviews lasted for approximately 30 minutes.

Data analysis.

Each interview was transcribed verbatim from audio-recordings. Transcripts were imported into NVivo 10 to facilitate analysis. Analysis was inductive and a thematic approach taken (Braun & Clarke, 2006). Authors SJ, KG, and ED met throughout the analysis to discuss emerging thematic categories. Data immersion and coding were completed independently and final themes agreed through discussion. The parent engagement group also provided comment and validated interpretations of themes. The researchers agreed when data saturation had occurred (defined as the point at which there was consensus across differing professional groups on issues discussed) and no further data collection was warranted.

Results

Four overlapping themes were identified: 1) Roles and responsibilities to support maternal mental health, 2) Issues dealing with maternal mental health difficulties, 3) Strategies to support maternal mental health and 4) Opportunities for improvement.

1. Roles and responsibilities to support maternal mental health.

Acknowledgements of maternal well-being.

All health professionals described the stressors that mothers commonly face parenting their child with a disability, and acknowledged maternal mental health difficulties were very common in families they supported.

I'd say a fairly high proportion of the mothers that I'm dealing with do have some sort of difficulties when it comes to mental health...I'm dealing with mothers who have got some difficulties with low mood and depression and there's certainly quite a high number of mothers with anxiety difficulties.

Allied health – Occupational therapist

Allied health and paediatricians also emphasised that the mother's mental health was paramount to their work with the child in driving good treatment outcomes.

It's essential to include a really good understanding of maternal mental health because in the vast majority of cases if a mum doesn't have the mental wellbeing to drive an intervention the child's prognosis isn't going to change.

Paediatrician

Shared responsibility.

All health professionals who are in contact with mothers (commonly reported as the GP, paediatrician, and allied health professionals) recognised a responsibility to support mothers' mental health, specifically to recognise when mothers were not coping and to suggest referrals for support. However, health professionals conveyed limited confidence over who takes responsibility for following up with mothers in practice.

I think it's whoever's (any health professional working with mothers) responsibility that that mum opens up to. It's their responsibility to deal with that information in the best way. Maybe it's not to then provide service as such but to help her to connect in with someone that can maybe.

Allied Health – Occupational therapist

In considering who was best placed to discuss mental health difficulties with mothers, frequency of contact and a long-term role with families were considered fundamental.

Maybe an allied health professional that they saw all the time so if they're just seeing their physio once every few months maybe not but if was a weekly physio appointment then I think they would be totally appropriate.

Allied Health – Physiotherapist

I think often the families know us well enough to come and tell us they're not going well.

General Practitioner

Paediatricians have an important role because we're often one of the only long term consistent figures in the lives of these families.

Paediatrician

Different levels of care.

Despite having a shared responsibility to notice when mothers were not coping and to act accordingly, different levels of care were described. Paediatricians considered their role was to recognise and refer to the GP given their limited time, whereas allied health professionals, particularly within ECIS, took a much broader approach to discussing and linking mothers with support. This related to allied health professionals' frequency of contact with families, breadth of role and knowledge of community support options, and longer duration of sessions. These typically occurred within the family home, which helped build rapport and trust with mothers.

There's only so much that I can do.... I just don't think I have the skills necessarily to recognise what supports they need and then if you do who do you refer them to and how do you support them?

Paediatrician

I think we're actually in a good position because we're the people that see them once a fortnight, developing a rapport with them. They start to trust us we hope. So, I think we are in that sense set up quite well to have these kinds of conversations.

Allied Health – Occupational therapist

We spend a while talking about their goals and how their child is developing. Then we might say and do you feel supported in terms of family, friends...and sometimes it's like no, 'there's no one else' and that is a link in to talk about if you wanted to talk to our psychologist.

Allied Health – Occupational therapist

One paediatrician described the GP as being primarily responsible for assisting mothers to access professional mental health support, as they are the 'gateway' to accessing mental health professionals.

I think if any of the allied health or doctors involved with the mother of a child see that the mother isn't coping, they need to tell them to see their GP and to have a chat about how they're feeling. I think the GP is the one who has got to do the organisation, because they're the one that is responsible for the mother.

Paediatrician

2. Issues dealing with maternal mental health difficulties.

Several issues made it challenging for health professionals to support mothers' mental health. Allied health professionals considered lack of training in adult mental health, low confidence in asking questions about mothers' emotional wellbeing, and role tensions in spending a larger proportion of time on the mother over the child, to be significant issues. In contrast, GPs and paediatricians were more confident given their role already focused on suggesting and making referrals. For GPs and paediatricians, challenges included the systemic barriers to mothers accessing mental health professionals, and beliefs that mothers did not prioritise their own wellbeing.

Lack of training.

In general, allied health professionals reported that their current role did not allow them to attend to mothers' mental health and they felt uncomfortable about this. They recognised its importance but felt it was outside their role and beyond their capability.

I don't have the skillset, I'm sure a lot of other physios maybe wouldn't have the skillset to be able to have those type of conversations.

Allied Health – Physiotherapist

I find it hard. I don't find that conversation easy..... we aren't really trained specifically to do that. I'm much more comfortable talking about the child's development.

Allied Health – Occupational therapist

Role tensions.

There was a sense of professional conflict over providing support that mothers need for their wellbeing and feeling qualified to do so. As with subthemes of *Shared Responsibility* and *Different Levels of Care*, health professionals were uncertain as to how following up with mothers' mental health fit into their current roles.

It's really hard because we have to draw a line sometimes between what our job description is and what we can provide. Although you can see that this mum is in great need it's actually not an area that we're qualified to be working in.

Allied Health – Occupational therapist

Allied health professionals struggled with the boundaries of their role in supporting mothers' mental health, specifically understanding how much support to provide for mothers' mental health over therapeutic needs of the child.

We know we need to address the mental health in order to make a difference with the whole family and with the child. But how much do we need to address it in order for that to happen? I'm not their mental health worker. I want to get in with this child.

Allied Health – Occupational therapist

Mothers' not prioritising their mental health.

Another challenge to health professionals discussing and supporting mental health of mothers was that they felt mothers were not willing to engage in support for themselves. That is, health professionals believed mothers prioritised their child over themselves to the detriment of their own mental health.

Some mums definitely prioritise the child's needs and don't see the importance of addressing or working on their own mental health and that's something that we hear time and time over.... They just don't value that and find it really hard to see the importance of that in light of what's going on for their child.

Allied Health – Psychologist

Other barriers were that mothers may not acknowledge that they had mental health difficulties or did not want to let down their guard to show they were not coping.

I think that mothers do sometimes put up barriers about 'I should be able to cope with this, this is what I have to do' and so mothers sometimes need to be given permission to not be coping some of the time.

Paediatrician

Systemic barriers.

All health professionals appreciated that accessing mental health support was challenging for mothers and that there was not enough resources to make it more accessible. Financial and time barriers were mentioned along with difficulty in securing childcare. Several professionals described the difficulty of mothers having to take their child to appointments for their mental health.

Time wise to fit it in, cost wise, even with a mental health care plan which makes it much more accessible, it's still a gap. Childcare, what to do with the kids if you do decide to go and see somebody, finding the right person to see. It's often just all put in the too hard basket.

Allied Health – Speech pathologist

They have to take their kid with them which is quite difficult and they're already attending lots of medical appointments already with their kid and then having to go see a psychologist is difficult. Then financially they're usually not working because they spend a lot of time caring for their disabled child so often there's financial issues and the costs of going to see a psychologist is difficult.

GP

It's often hard for the parents to talk about their own mental health around their children because they don't want to stress the child.

Pediatrician

3. Strategies to support maternal mental health.

As per the different levels of care across professions, strategies taken to support mothers' mental health also differed. None of the health professionals described screening or assessing specific mental health symptoms, but rather engaging in open discussion if signs of poor mental health were evident, and consequently referring on. All health professionals focused on the management (actions) they took rather than how they identified that there was a problem.

Initiating discussion.

One GP talked about regularly checking in with the mother as part of standard care, including normalising mothers' experience.

I would have mentioned it on and off as an option that you might need support, this is a stressful environment, any time you want it you come and tell me. So, it would be probably an ongoing discussion we'd be having about 'how are you?' and 'how are things'?
GP

Normalising mum's frustrations or exhaustion... just acknowledging it and to say that's a normal part of the process.

Paediatrician

One allied health worker described the importance of raising access to support early on rather than waiting until problems arose.

Trying to open up some of those discussions early on, trying to make suggestions or link them into their GP or support groups that are out in the community.
Allied Health – Psychologist

Mothers were also encouraged to engage in help-seeking.

If I recognise it as a problem I will raise it with them and tell them that it's important for them to look after themselves. You've got to be very careful the way you do it but once you've got a relationship you know how you can deal with them and you can talk to them.

Paediatrician

Referrals.

All paediatricians reported that they contacted the mother's GP so they were aware of the need for mental health support for the mother.

I would make sure that they went and saw their GP and sought assistance and I would contact the GP and certainly at the very least write to him.

Paediatrician

Access to multidisciplinary teams.

Allied health professionals working within ECIS reported seeking advice from team members who were psychologists or social workers about how to support mothers' mental health.

I'll say we have a psychologist, so if you feel you need to talk to somebody or your husband or anyone in the family or individually, together.

Allied Health – Occupational therapist

Additionally, paediatricians who worked within multidisciplinary teams would refer mothers to a social worker.

We have a very experienced social worker on our team who's also got qualifications in family counselling. She's worked in this area for 25 years and knows all of the agencies and all of the supports and is infinitely patient and she's a fantastic resource for these families.

Paediatrician

I would refer them to our social worker as well who could put them in touch with community supports and have a realistic talk to them about what can be done to support and to help them.

Paediatrician

Linking into parent support groups.

Allied health professionals particularly within ECIS would link mothers to parent support groups that ran at the ECIS site.

We try and run some parent programs that whilst they're not specifically focused around wellbeing, the importance of looking after yourself is emphasised

Allied Health – Psychologist

We have a parent support group where the parents come and we have a carer for the children in the room.. We do lots of self-care things like we've done yoga, meditation, hand massage, making beauty products.

Allied Health – Social worker

4. Opportunities for improvement.

Better access to training.

Allied health professionals described the need for training in how to have difficult conversations about maternal mental health and better understanding of clear and simple referral pathways. One paediatrician reported the need for greater education of all health professionals, such as lectures within hospital settings.

I think if everyone had some kind of general training around how to have those conversations. I don't think it should be limited to somebody like a psychologist. We're not talking about treating their mental health difficulties but about raising awareness, opening the discussion and breaking down some of the beliefs that the family might have around it not being important or valued.

Allied Health –

Psychologist

If I was really worried about someone and they weren't bringing it up and you had to try and delve into it a bit more that's challenging.. Probably a little bit more specific PD (professional development) around that would certainly help.

Allied Health – Speech Pathologist

I think it'd be really nice to hear more about it (supporting maternal mental health) I think in public lectures.

Paediatrician

Online list of available resources.

One GP suggested that a website with mental health information specific to mothers who have a child with a disability would be helpful.

I think maybe having a go to like a spot where this is like a website where you can look. You get a link from the Royal Children's or something for these are some resources, something like that. So, having a one stop spot where there are links or resources.

GP

Better access to other health professionals.

Most health professionals commented on the need for a better, community-based system to support mothers' mental health and overall wellbeing, as opposed to relying on private psychologists that were often expensive and difficult for mothers to attend. One allied health professional within ECIS also raised the need for more mental health professionals based at the service, who could work with the physiotherapists, occupational therapists and speech pathologists in addressing mental health difficulties.

There needs to be a better system in the community that can actually provide that psychological input.

Paediatrician

More ability for multidisciplinary work so seeing the family in the context of a whole team. We know as paediatricians there's social workers or mental health

professionals but often getting in the door involves cost or time or geographic challenges.

Paediatrician

That's something that's missing like more psychologists or social workers or mental health workers as part of early childhood services.

Allied Health – Social worker

Discussion

This study aimed to explore health professionals' perspectives on supporting the mental health of mothers of children with a disability, specifically their roles, actions, and challenges. Our findings indicate that mothers' mental health is of high relevance to health professionals working with families of children with a disability. Different levels of responsibilities and types of challenges to providing support for mothers were identified by health professionals from various disciplines. A pathway of care leading to the GP who was the 'gateway' to accessing a mental health professional such as a psychologist was identified. There was little information on how health professionals identified mental health difficulties in mothers. None of the professionals described using screening tools or formally assessing mental health symptoms.

The study identified several challenges for health professionals in their role to support mothers' mental health. Although allied health professionals' within ECIS felt that they were in a good position to support mothers given their frequent contact with families, they reported lacking confidence in initiating conversations about mental health, and role tension in support for the child versus support for the mother. Additional training was considered important by these professionals. Lack of training has been found by other authors as a major barrier in adequately identifying maternal mental health difficulties (Nakku et al., 2016; Khan, 2015; Russell, Lang, Clinton, & Adams, 2013).

The study also highlighted that challenges were perceived at the level of the mother as well as at the broader system. The majority of health professionals reported that mothers did not prioritise or acknowledge struggles with their mental health, which made it difficult for them to be addressed. Difficulties mothers experience discussing their mental health with health professionals have been identified in previous studies. Research on a sample of midlife Australian women (Outram, Murphy, & Cockburn, 2004) found barriers to seeking help included mothers' feelings of weakness in asking for and accepting help, feelings of shame and embarrassment and fears of judgement, fear of painful self-discovery and the belief no-one can help.

A further challenge was the lack of readily accessible supports for mothers. Professionals, especially the GP and paediatrician, focused on linking mothers with psychologists where appointments could be costly and difficult to attend.

Implications.

We found that the mental health of mothers of children with a disability is not a hidden issue to the health professionals working with families. However, there is a significant gap in skill about how to raise discussions about mental health, and a lack of knowledge about the types of supports that are readily accessible to mothers. Moreover, education is required to ensure discussions about mental health do not impact on professionals' ongoing therapeutic work with the child and the boundaries of their role are clearly understood.

Currently, there are no national guidelines that explicitly describe how to respond to mental health concerns in mothers of children with a disability, only general guidance for responding

to adult mental health concerns. Furthermore, guidelines specifically developed for health professionals within ECIS, only provide broad references to strengthening parenting knowledge, skills and competence and facilitating access to community based services to meet family need (Division for Early Childhood recommended practices in early intervention, 2014; National Guidelines for Best Practice in Early Childhood Intervention, 2016). None of the health professionals reported the use of established frameworks or guidelines to identify mental health concerns, resources that should be developed and tailored to mothers of children with a disability and embedded within professional practice.

A further implication is the common belief that mothers do not readily engage in conversations about their mental health and necessary supports, and the lack of accessible professional support available. Further research is needed to understand the perspectives of mothers in accessing such support and how this may be best accomplished. New models of care around identifying and supporting mothers' mental health may be helpful such as mindfulness-based stress reduction, which could be led by peer-mentors (Dykens, Fisher, Taylor, Lambert, & Miodrag, 2014). Other approaches such as a health and empowerment program for mothers of children with a disability have also been proposed (Bourke-Taylor & Jane, 2018).

Embedding support for mothers' mental health will also require policy change in a climate where services are focused on the child. Family-centred care is vital to ensure best outcomes (Kuo et al., 2012) but continues to be hampered by factors such as lack of external resources and reimbursement for the time necessary for implementation. Better integration between ECIS and mental health services may also serve the unique needs of families struggling with stress and depression whilst coping with their child's special needs (Alvarez, Meltzer-Brody, Mandel, & Beeber, 2015).

Limitations and future study.

Limitations to this study include a small sample size. However, it represents the heterogeneity of health professionals working with the mothers of young children with a disability. Health professionals participating in this study may not be representative of a larger sample, as their willingness to take part may reflect a response bias towards addressing mothers' mental health in children with disabilities.

Results from this study may be used to inform future qualitative and quantitative studies. Further qualitative study could be undertaken with allied health professionals working with ECIS to gain a more in-depth understanding of the barriers and facilitators to supporting mothers' mental health, to inform professional development programs. Large quantitative survey data across professional groups would also be valuable in informing the gaps in supporting mothers' mental health with a focus on identification and detection, and management, for example Olson et al. (2002).

Conclusion.

Mental health is a key factor in enabling mothers to fully participate in society and their community. It is also a key ingredient in their child's health and wellbeing. Child health

professionals are well placed to support mothers' mental health. However, despite understanding the mental health challenges mother face, those working closest to families do not always feel confident to manage mothers' distress or experience challenges when they try to do so. Interventions should be designed to empower health professionals, change policy to allow parental support in child services, and provide integrated care pathways and recommendations for referral. In turn, this will improve mothers' mental health and break existing vicious cycles adversely impacting mothers, improving their and their children's lives now and in the future.

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