

# PARENTAL STRESS IN FAMILIES OF YOUNG PEOPLE WITH AN INTELLECTUAL DISABILITY: THE NURSES ROLE.

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## ABSTRACT

This study examines stress in the parents of adolescents and young adults with an intellectual disability and compares it with stress reported by parents with offspring without an intellectual disability. An initial qualitative pilot study lead the authors to Baine et al's Stress Scale. The Baine et al scale is relatively new and addresses aspects of stress not previously investigated among the parents of people with an intellectual disability, namely, stress from the difficult relationship with health professionals and service providers and negative community attitudes to people with an intellectual disability. Because of the relevance to nurses, particular interest is paid to stress from the relationship parents have with health professionals and service providers.

The study found significantly greater stress in the parents of young people with an intellectual disability in all aspects of stress examined, including stress from the individual with the disability, internal family stress, stress from the financial strain of having a family member with a disability, stress from community attitudes and stress perceived from the relationship with health professionals and service providers.

These findings are distressing in the light of government and service agency policies of community care and independent living. This paper makes recommendations relevant to nurses and identifies difficulties for parents of young people with an intellectual disability in the implementation of current government policy.

## INTRODUCTION

Adolescence is a period of transition when young people move from being dependent on their parents to being increasingly independent.<sup>1</sup> For many parents, their son's or daughter's transition from childhood to adulthood can be a difficult period. There are many challenges for the young person in attaining adult status and learning to accept adult responsibilities, and one of the most useful resources for them during this transition is their family. This is as true of people with an intellectual disability as it is for people without.<sup>2</sup>

Although this transition period can be difficult for parents, there is substantial literature attesting to the fact that parents with offspring with an intellectual disability suffer higher stress levels than parents with offspring without an intellectual disability.<sup>3,4</sup> These parents experience stress from lack of support,<sup>5</sup> their difficulty accepting their son or daughter's disability,<sup>6</sup> from financial hardship and marital problems related to the family member with a disability.<sup>7</sup> This stress can have a profound effect on the family and the relationships within it<sup>8</sup> and is often the major factor when parents of people with an intellectual disability make a decision to seek services.<sup>9</sup>

Unfortunately, much of the research addressing stress in the parents of young people with an intellectual disability uses models of stress which focus on problems within the family.<sup>10-12</sup> Therefore, much of the literature only addresses internal factors such as level of disability, behaviour problems and family structure as sources of stress<sup>13,14</sup> and ignores external factors such as the attitudes of the community and the way services are delivered.

This inward-looking orientation to parental stress invariably leads to viewing the parents as the problem. The research finds stress, which is interpreted as deficits or pathology within the family, because that is the orientation of the measures.<sup>15-19</sup> A possible reason for this may be that much of the research focusing on intellectual disabilities has been conducted by allied health professionals and there is little evidence of input by the parents of people with an intellectual disability into the process of research design. The study undertaken by the authors attempts to remedy this by conducting an initial qualitative study asking the parents of young people with an intellectual disability to identify the issues that are important to the experience of parenting offspring with an intellectual disability.

## INITIAL QUALITATIVE STUDY

The initial study was conducted in order to identify themes that parents thought were important to the experience of having a son or daughter with an intellectual disability.

Interviews were conducted with five parents in four families with a son or daughter with an intellectual disability, in-depth interview strategies used with open-ended questions for data collection. Data was recorded by the author using field notes. The data collection consisted of two meetings with each family. The first meeting was to collect the data. The second was used to allow the families the opportunity to evaluate the written summaries of the first meeting and discuss the importance of the themes identified.

The main themes to emerge were dissatisfaction with services and health professionals, negative community attitudes, anxiety about sexuality of offspring, the issue of dependence and independence and the emotional pain of having a son or daughter with a intellectual disability. The most important issues identified by parents were external to the family and concerned the difficulty parents have with health professionals and service providers. Parents complained that their opinions were not taken seriously by health professionals and service providers. There is some support for these findings in the literature.<sup>20-25</sup>

The results of this initial study were used to set the criteria for selection of the most appropriate model, design and measure for the second phase of the study. A model of stress that addresses the issue of difficulties in the relationship parents have with health professionals and service providers and community attitudes has been developed by Baine et al<sup>26</sup> and therefore was chosen for this second phase of the study.

## MODEL OF STRESS

The Baine et al model is new and therefore has not been well researched but the model has high construct validity because it is based on experiences reported by parents of young adults with an intellectual disability in qualitative and quantitative studies. Baine et al used the literature to draft a conceptual matrix to represent the stresses experienced by the parents. They then used a grounded theory approach to study 12 parents from eight families. These parent opinions were used to refine the matrix from which a questionnaire was developed. The matrix was trialled with 75 parents who had a son or daughter with an intellectual disability. Using the data from this study, Baine et al developed a model for stress which includes five categories, which are discussed below, and was operationalised as a stress scale.

The characteristics and difficulties of the son or daughter with an intellectual disability comprise the initial category of Baine et al's model which includes items such as expression of sexuality, problems related to dependency needs, physical management problems and care demands, and the lack of social skills.

The second category in Baine et al's model deals with stress from the impact on the family of the young person with an intellectual disability. Often, lack of real support and the cost of long-term care means parents have to learn to live on less. As family resources are further stretched or focused on the person with a disability, there can be resentment of other siblings and fathers can become less involved. Siblings experience problems of low tolerance and embarrassment, and parents feel the lack of social support and must put in greater efforts to become skilled advocates for their sons and daughters.<sup>27</sup>

Baine et al.,<sup>28</sup> in their next category, identify stress arising from inadequate financial resources. The parents in Baine et al's study were particularly frustrated by lack of government funding. Parents with offspring with an intellectual disability in the USA spend 7% of their income on health and personal care of their son or daughter.<sup>29</sup> While in Australia, Mathews, Graham, and Doyle<sup>30</sup> found the extra cost of caring for a child with a disability was made worse by the indirect cost of the mothers' restricted opportunity for paid employment. This stress was exacerbated by government funding agencies whose policies were always changing.<sup>31</sup>

A further factor contributing to stress in parents is attitudes to, or acceptance of, their son or daughter with an intellectual disability. Negative attitudes towards the individual with disabilities was observed in the general community, in neighbours, among peers and among health professionals by Baine et al.<sup>32</sup> Parents with a son or daughter with a disability find that the people around them often respond negatively to their son or daughter.

The final of Baine et al's categories is stress from the relationship with health professionals and services. Here Baine et al found parents were dissatisfied with the availability and the quality of services, which were few, inadequate and costly. Often, when the relationship with professionals is unsatisfactory, there appears to be frustration and stress around issues of not being believed, lack of appropriate services and the need for advocacy.<sup>33</sup> Parents sometimes feel service providers put blocks in the way.<sup>34,35</sup>

Having identified the most appropriate model, the aim of the second phase of the study was to investigate the stress reported by parents of adolescents/young adults with an intellectual disability. The literature reviewed above leads to the prediction that these parents would show significantly higher subjective stress levels in all aspects of stress than the parents of young people without an intellectual disability. In particular, it was expected that stressors such as community attitudes and service provision, would emerge as problematic for parents of those families with offspring with an intellectual disability. The outcome is of direct relevance to nurses because of the focus on parental relationships with health professionals.

## METHOD

The design for the second phase of the study was a two-group, five-variable comparison. The data were analysed using *t* test and Chi-square.

A total of 102 responses were included in the study, 44 (43.1%) having a son or daughter without an intellectual disability and 58 (56.9%) having a son or daughter with an intellectual disability. Of the participating parents, 17 (16.7%) were from the Gold Coast, 33 (32.4%) from other parts of Queensland including Brisbane and Toowoomba, 44 (43.1%) from the New South Wales north coast, and 8 (7.8%) from western New South Wales.

The age range of the sons and daughters of the participants was 15 to 26 years (see Table 1).

**Table 1: Age and sex of offspring of the families**

	female n	male n	total n	age M	age sd
Without	31	13	44	18.5	2.54
With	27	31	58	18.27	2.27
Total	58	44	102	18.4	2.42

**Note**

Without = A family that has an adolescent/young adult son or daughter without an intellectual disability.

With = A family that has an adolescent/young adult son or daughter with an intellectual disability.

## INSTRUMENT

The self report stress scale published by Baine et al<sup>36</sup> was used in this study. It has five sub-scales, discussed above, each of which identifies an area or category of stress.

This questionnaire uses a five-point Likert scale ranging from "no stress" to "extreme stress" in each of the identified sub-category items. The items are scored 0 for no stress through to four for extreme stress. Scores for each stress sub-scale are made up of the mean of the scores of the items. A score for total stress is then arrived at by adding the scores of the five sub-scales.

While this scale has only recently been developed, and detailed psychometric evaluation is not yet available, Baine's five categories of stress have general support from

the literature and the scale was developed with the help of families of people with offspring with intellectual disabilities which supports its validity.

## PROCEDURE

Parents with an adolescent/young adult son or daughter without a disability were contacted through regional universities and high schools in northern NSW and south-east Queensland. Parents with a son or daughter with an intellectual disability were contacted through respite services, recreation services, and employment services in northern NSW and the Gold Coast. The organisations were sent 320 packages to distribute, consisting of the questionnaire and a stamped return addressed envelope and 110 (29%) were returned.

## RESULTS

All statistical analyses were performed using Statistical Package for the Social Sciences for Windows Version 6 (SPSS). An alpha level of .05 was used for all statistical tests.

Reliability coefficients were calculated using Cronbach's alpha for the overall stress scale and each of the five sub-scales. Reliability coefficients were found to be high in all the stress sub-scales with scores of: individual stress =.92, family stress =.86, attitude stress =.90, finance stress =.87, and services stress =.95 and an alpha for the overall scale of .85. These reliability scores demonstrate high internal consistency and support the selection of Baine's Stress Scale as a reliable measure.

As hypothesised, the parents of young people with an intellectual disability reported more total stress than parents in the control group. The total mean stress scores for parents with offspring with an intellectual disability ( $M = 6.08$ ,  $SD = 4.24$ ) and parents without offspring with a intellectual disability ( $M = 1.72$ ,  $SD = 1.67$ ) were compared using a  $t$  test, and a significant difference was found ( $t = 7.13$ ,  $df = 78.33$ ,  $p < .001$ ) between the groups. These results indicate that parents of adolescents/young adults with an intellectual disability reported significantly higher total stress than the parents with offspring without an intellectual disability, as predicted.

In order to examine more closely which aspects of stress contributed to this significant difference between the groups,  $t$  tests were conducted using the data from the five sub-scales of stress. There was a significant difference between the mean stress scores of the groups in all of the sub-scales of stress (see Table 2).

**Table 2: Means and  $t$ -test scores for both populations in stress scales**

	Without M(SD)	With M(SD)	$t$	df
Individual	0.39(0.32)	1.38(.80)	-8.38 ***	81.36
Family	0.31(0.33)	0.99(.79)	-0.58 ***	80.95
Attitude	0.26(0.39)	0.99(.90)	-5.45 ***	81.94
Finances	0.57(0.56)	1.42(1.36)	-4.25 ***	80.09
Services	0.17(0.29)	1.31(1.14)	-7.29 ***	66.53

**Note**

Without = A family that has an adolescent/young adult son or daughter without an intellectual disability.

With = A family that has an adolescent/young adult son or daughter with an intellectual disability.

\*\*\*  $p < .001$

Consistent with the results of the pilot study, the stress emerging from dealing with health professionals and service providers was significantly higher than in parents with non-disabled offspring. The individual sub-scale includes items such as expression of sexuality, problems related to dependency needs, physical management problems and care demands, and the lack of social skills. In the sub-scale of family related stress, mothers and fathers of young people with an intellectual disability identified stress around issues of sibling relations, sociocultural characteristics of the family (e.g. family constellation and socioeconomic status), and family social and material resources. In the sub-scale of attitude, parents with offspring with an intellectual disability found significant stress in the attitude of others to their son or daughter. Their own attitude to and their personal philosophy about the intellectual disability, and the attitude of health professionals also caused significant stress in their lives. The extra financial burden of having a son or daughter with a intellectual disability was an

additional stress for parents with offspring with an intellectual disability. The lack of financial support and the low wages for people with an intellectual disability also caused stress.

To further examine the reported stress from service providers and health professionals, individual items of the sub-scale were analysed using a Kruskal-Wallis one-way analysis of variance test. This test was used to examine the difference in the ranking of the responses to the individual items of service-related stress and stress from professional attitudes between the two groups.

As predicted, there was a significant difference in levels of stress reported by the two groups in all the service scale items. This demonstrates that stress related to such issues as the quality and availability of professional services, attitudes of health professionals, relief care, and transport was high in the parents of young people with an intellectual disability (see Table 3).

**Table 3: Mean ranking of service and professional related items stressfulness**

	Without	With	chi-square
Transport	38.51	61.35	17.29 ****
Respite	38.36	61.47	22.64 ****
Guidance	33.26	65.34	37.37 ****
Residential	37.05	62.47	24.70 ****
Grants	42.13	58.61	10.10 ****
Transition	34.35	64.51	30.62 ****
Professional	32.60	65.84	40.00 ****
Availability	37.30	62.28	25.13 ****
Leisure	34.34	64.52	31.63 ****
Attitude of professionals	39.10	60.97	18.27 ****
**** P < .0001			

As expected, these results indicate that parents with a son or daughter with a intellectual disability do report suffering considerably more stress than other parents from a number of different aspects of their relationship with services and health professionals.

## DISCUSSION

As predicted, on the basis of the initial study and a review of the literature, parents of young people with an intellectual disability were found to report significantly higher levels of total stress than the parents of young people without an intellectual disability. This stress was higher in all the categories measured using the Baine's scale. These categories include individual stress, family stress, stress from relationships with services, attitudinal stress, and financial stress.

Individual stress, which is generally the behaviour of the person with a intellectual disability, was also reported as stressful in studies by Baxter,<sup>37</sup> Orr, Cameron, Dobson, and Day,<sup>38</sup> and Zetlin and Turner.<sup>39</sup>

Family issues have also been found to be a source of stress for parents, particularly coping with the independence/dependence struggle of young people and in accepting that their sons and daughters with a disability can live safely without their support.<sup>40,41</sup> Young people with an intellectual disability socialise mainly with their families and are dependent on them for support.<sup>42</sup> This dependence can create strain and even resentment in the family and increase the likelihood of out of home placement.<sup>43</sup>

Financial hardship associated with the experience of having a son or daughter with a intellectual disability is a common finding and consistent with Mathews et al<sup>44</sup> in Australia and Bienbaum and Cohen<sup>45</sup> in the USA. This financial hardship is generally a result of the restricted ability to earn income (as a result of having offspring with a disability) as well as the added expense of the disability.<sup>46</sup>

As noted in the introduction, much of the research into family stress has used models and measures which focus on issues within the family, thus directing much of the blame onto the family.<sup>47</sup> As nurses take a more holistic approach the authors believed external factors should also be considered.

This study has demonstrated that factors beyond the control of the family can also be significant stressors, for example the attitudes of others and the relationship with health professionals and services.

In the initial study it was noted by parents that people were often willing to help but were not interested in including their sons and daughters with an intellectual disability in their social network. It seems that although the government policy of including people with an intellectual disability in community life has been established for more than 15 years, the reality is that they are often excluded. Many people with an intellectual disability appear to be doubly disadvantaged, in that they have a disability and the non-acceptance of the people around them to contend with. Clearly more research needs to be done in this area to offer direction to policy makers and health professionals on changing community attitudes.

One source of stress was selected as the focus of particular attention in this study, that of dissatisfaction with health professionals and services. This source of stress has been noted previously by Wolfensberger<sup>48</sup> and Dempsey.<sup>49</sup> This finding was particularly distressing as nurses make up a largest portion of health professionals, so it is of concern to nurses that families under stress list health professionals and service providers as a further source of stress, especially since the overall mission of nurses—especially those working with disability services—is to offer support and to relieve the pressure. Stress from the relationship with health professionals and service providers was first noted in the initial study, where it appeared that parents were frustrated with health professionals who seemed to ignore their views. This stressor seemed more frustrating than many other stresses in their lives and yet, surprisingly, this source of stress has been addressed by few researchers in this field. The fact that parental stress from the relationship with health professionals and service providers has been neglected by many researchers is significant because the level of stress reported in many studies may consequently have been appreciably underestimated.

The results of this study suggest that parents see a need for greater advocacy on their part and involvement in services they perceive as inadequate. This often becomes a long struggle which starts as a watchdog and advocate role but inevitably degenerates into a fight for scarce resources, lobbying politicians for funding and arguing with health professionals.

The policies of the New South Wales and Queensland governments relating to people with an intellectual

disability are such that the family should be a major support network.<sup>50</sup> Policies also advocate that the family be given every opportunity and support to care for its member with a disability with adequate professional help and services so as to minimise their stress. Clearly this is not happening and until the governments can match the rhetoric with user-sensitive, quality service they will continue to depend on the goodwill of parents to provide much of the support to their offspring with an intellectual disability. This study also shows that such support for their sons and daughters with an intellectual disability will be at the parents' cost in terms of the stress they must endure.

## LIMITATIONS OF THE STUDY

In hindsight, some weaknesses were identified in the design of this study. There is a possible bias in the sampling of the population of parents of young people with an intellectual disability. The participants came mostly from the users of respite services, employment services and recreation services for people with an intellectual disability, and therefore excluded people who do not use such services. People who do not use services may have been less critical of the services or perhaps even more critical of them, depending on why they choose not to use them. The population of parents of people without an intellectual disability came from ex-year 11 and 12 students and university students. Many of these young people, it could be argued, are high achievers (i.e. attending university) or from high achieving families.

Baine et al's model of stress at this stage has not been well researched, therefore this study would have been strengthened if the model was more established.

## CONCLUSIONS

Parents of people with an intellectual disability are a very stressed group within the community. This has long been the case and lifelong stress is accepted as an inevitable consequence of having a child with an intellectual disability. This research study not only confirmed this but, more importantly, demonstrated that one of the major sources of stress reported by parents involves factors outside the family, such as service and professional personnel set up to support them. The very solution set up to ease the stress is perceived as yet another aspect of the problem!

Through the inclusion of both qualitative and quantitative assessment procedures, this study was able to demonstrate that dissatisfaction with existing services and the fight for additional services are major contributors to parental overload for those parents raising adolescents with an intellectual disability. Never having their opinion sought nor ever being credited by health professionals as having anything useful to contribute were particular examples that increase frustration.

For nurses working with parents with a son or daughter with an intellectual disability, there are both general and specific concerns warranting sensitivity and support. While all of the categories of stress noted in the study may not be relevant to every parent, greater sensitivity and awareness by nurses may serve to alleviate some of the external pressures on the family so that relations can be characterised by support, empathy and understanding.

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