



Mermaids' Parents Survey 2014

Introduction

Mermaids Charity was formed in 1995 with the following aims:

- To support children and teenagers coping with gender identity issues
- To offer support to parents, families, carers and others
- To raise awareness about gender issues amongst professionals and the general public
- To campaign for the recognition of gender identity issues and for an increase in professional services

Mermaids' membership is exclusive to young people under the age of 20yrs with gender dysphoria and their parents. In August 2014 parents were asked to complete an online survey regarding their experiences within the Gender Identity Development service in the UK. The results are summarised below.

Survey Results

44 families completed the survey.

Age at presentation

48% reported their children displaying unhappiness with their assigned gender under the age of 7yrs, all of whom had sought medical help by the age of 7.

Present age

The age of the children of those families who completed the survey and are presently attending the Tavistock and Portman Gender Identity Development Service (GIDS) at the time of completion is below.

Present Age (yrs)	7 to 10	11 or 12	13 or 14	15 or 16	17+
Number	6	3	5	9	9

Waiting time for first appointment with psychologist

Time waiting	Up to 8 weeks	9 to 12 weeks	13 to 16 weeks	17 to 18 weeks	19 to 20 weeks	21 to 24 weeks	25 to 26 weeks
Number	4	5	13	2	4	2	3

24 (73%) reported waiting 18 weeks or less for their first assessment and 9 (27%) others waited up to 26 weeks.

Impact of waiting times for initial assessment

Parents were asked about how they thought the wait for the first appointment had impacted on their child's wellbeing. The results are split into the child's age groups in the table below. Parents were asked to mark each category relevant to their child.

	Age (yrs)					Total
	7 to 10	11 or 12	13 or 14	15 or 16	17 +	
No impact	3	1	4	2		10
Positive effect on mood		1	4	1	1	7
Decreased gender dysphoria		1	1			2
Negative effect on mood	2	4	10	10	1	27
Increased gender dysphoria	1	1	2	8	7	19
Depression	1	2	5	7	10	25
Other mental illness	1	1		2	4	8
Self-harm once			2	2	2	6
Self-harm more than once	1		2	4	5	12
Attempted suicide				1	2	3
Restricted food intake	1		2	3	5	11

Forty parents responded to this section. Ten stated that waiting time did not affect their child. However six of these also stated that there were some negative effects of waiting therefore in only four cases can it be said that there was no negative effect on their child's mental health. There were 9 comments of improved mental health (positive effect on mood or decreased gender dysphoria), seven of these are from parents who reported no effect of waiting. Three parents reported that during the wait for the initial assessment, their child's mood improved but also reported an increase in their gender dysphoria. Another reported an improvement in mood but an increase in depression so this case should be excluded from this analysis.

From the data provided, only five parents thought that the wait for the initial assessment had no impact on their child's mental wellbeing. Four parents responded that they didn't know whether there was any impact or not.

There were 111 individual reports of decreased mental wellbeing with three (7.5%) individuals who attempted suicide during this waiting time. One child waited 16 weeks for the initial assessment, another 20 weeks and the third parent didn't state the waiting time.

Eleven (27.5%) parents reported an increase in their child restricting their food intake whilst awaiting the first appointment.

It is clear from the table above that the incidence of depression, increased gender dysphoria, suicidal tendencies and development of poor eating habits increases with age.

Waiting times to see an endocrinologist

Parents of young people who were already pubertal at the time of referral to the GIDS were asked how long they waited from referral to the GIDS until they were seen by an endocrinologist. The details are in the table below:

Time (months)	Up to 4	5-6	7-8	9-10	11-12	13-14	15-17	24	Still waiting
Number	1	1	1	4	3	1	1	1	5

Time to receiving first medical intervention from first endocrinology appointment

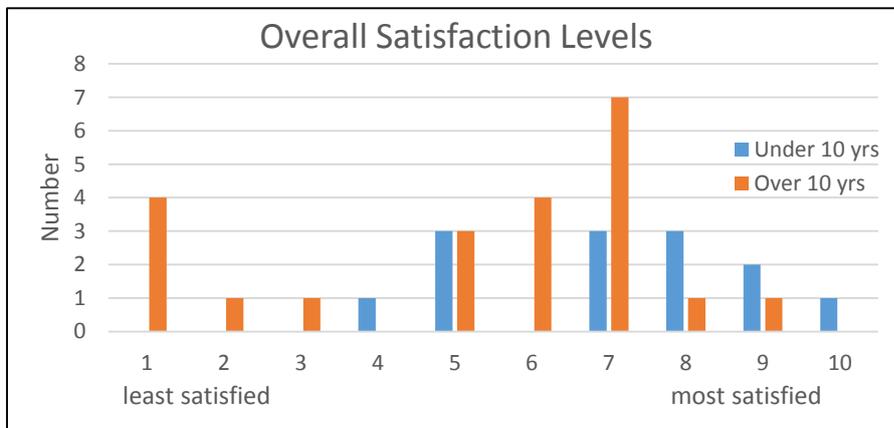
The median waiting time from referral to the GIDS to see an endocrinologist is 10-11 months. The range of time to receiving blockers from the first appointment was on the day of the first appointment to eight months. There was a median wait of 3-4 months from seeing the endocrinologist to receiving physical intervention. The reasons for delay in prescribing were reported as being communication errors between endocrinologist and administration on two occasions, awaiting test results on one occasion and clinic waiting times on two occasions. Therefore for those who are already pubertal at the time of referral, the median time from referral to the GIDS and receiving first physical intervention is 13 to 15 months.

Effect of attending the GIDS on the young person’s mental health

	Makes emotional state much worse	Makes emotional state worse	Does not alter emotional state	Improves emotional state	Improves emotional state greatly
Effect of thought of attending	4	15	10	10	3
Actual impact of attendance	5	12	11	9	4

45% of parents felt that their child’s emotional wellbeing deteriorated on the run up to their appointments, the young people find the thoughts of the assessments distressing. 45% of parents also reported a deterioration in their child’s mental health after the appointments at the GIDS.

Overall Satisfaction Levels



Satisfaction levels varied within the age groups of the young people attending the GIDS. Lowest satisfaction levels were only seen with those parents of young people over the age of 10 yrs.

Parent’s satisfaction with the endocrinologist’s care

Very Dissatisfied	2
Dissatisfied	0
Neither satisfied nor dissatisfied	4
Satisfied	11
Very satisfied	8

Participants' aspirations and wishes

Participants were asked "I feel my child's concerns and aspirations are taken into consideration when care is planned by the gender identity service" and "I feel that as a parent I am listened to and my opinions are taken into consideration when my child's care is planned by the gender identity service". 53.75% stated that they felt their child and their aspirations were taken into account when treatment was planned. 35% felt that their view point was not taken into consideration and 11.25% neither agreed nor disagreed.

Aspirations and wishes are taken into account	Young people	Parents	Total
Strongly disagree	7	6	13
Disagree slightly	6	9	15
Neither agree nor disagree	5	4	9
Agree slightly	12	12	24
Strongly agree	10	9	19

Communication and appointments

Given enough notice for appointments	Total
Not usually	4
Varies, sometimes yes, sometimes no	6
Yes always	16
Yes usually	14

Ease of getting answers to queries from the GIDS	Number	Percentage
Very difficult	6	14.6
Difficult	8	19.5
Neither easy or difficult	6	14.6
Easy	8	19.5
Very easy	5	12.2
I've never tried to contact them	8	19.5

I am happy with the distance I have to travel to my appointment	Number	Percentage
Strongly agree	9	21.4
Agree slightly	9	21.4
Neither agree nor disagree	3	7.1
Disagree slightly	8	19.0
Disagree strongly	13	31.0

Discussion

This survey collected the thoughts of the parents of 44 children and adolescents with gender dysphoria who ranged in age at the time of data collection from 7 to 17yrs. 40 of the responders were parents of children who were already pubertal at the time of referral. 27% of all those who responded had waited over 18 weeks for their initial assessment with the GIDS.

Parents reported that the wait for the first appointment had a negative impact on the mental health and wellbeing of 31 (77.5%) of the 40 young people included in the survey; three (7.5%) had attempted suicide whilst on the waiting list to be seen for the first time. Only five (12.5%) parents responded that they didn't think there was any negative impact from the wait with a further 4 (10%) not knowing if there had been any impact or not.

Behavioural and emotional problems are well recognised in the young trans* community [1]. 19 of the 31 parents had contacted the GIDS to report deterioration in mental health and wellbeing. On only one occasion did this result in an expedited appointment. This case was not a child who had been self-harming, had no depression or other mental illness and was not restricting their food intake.

27.5% of parents reported their child restricting their food intake whilst waiting for the first appointment. Many young people with gender dysphoria will severely restrict their diet in an attempt to delay the onset, or slow down progression of puberty. Trans boys in particular restrict their calorie intake in an effort to inhibit breast development and stop periods. This has serious consequences to both their physical as well as mental health.

The median time (for those who are already pubertal) from referral to receiving medical intervention is 13-15 months. This time translates into interminable torture for gender dysphoric teenagers who see their body changing throughout this period and are desperate to halt those changes. This is often happening at an important time in school where GCSEs are approaching. Although effect on education was not investigated in this survey, many parents report children missing school and failing academically as a result of their gender dysphoria. Again it is well recognised that "The experience of full biological puberty, an undesirable condition, may seriously interfere with healthy psychological functioning and well-being. Suffering from gender dysphoria without being able to present socially in the desired social role or to stop the development of secondary sex characteristics may result in an arrest in emotional, social, or intellectual development" [2]. In 2011 the Dutch specialists stated "Pubertal suppression averts the despair of gender dysphoric adolescents because of their physical changes and it may contribute to more self-confidence when socially interacting in adolescence and adulthood" [3]. This is not something that can afford to be delayed.

Some parents report an initial improvement in mental health once the referral to the GIDS has been made but go on to report serious decline in mental health whilst waiting for assessment and medical intervention.

There is presently NO choice for children and adolescents seeking care for gender dysphoria in the UK and the present service is seen by parents as being slow to access and slow to treat. There is only one service within England and Wales; the Scottish service will not agree to see children from outside of Scotland. There is NO private provision for under 16s in the UK either. Parents therefore have no choice but to use the Tavistock and Portman service. A number of parents express deep dissatisfaction with the service but they have nowhere else to go. The only alternative is an expensive trip abroad that is out of financial reach for most families. Two of the families in this cohort have decided the wait for NHS treatment is too long for their child and have travelled abroad for early care.

45% of families reported that their child's emotional health deteriorated on the run up to their appointments and another 45% stated that their child's emotional health suffered in the period of time following the appointment. It is known that young people with gender dysphoria "have a more anxious nature as compared to their normal counterparts" [4]. This survey did not ask for reasons why that may be but it is possible that the young people feel that the appointment is so important that they find it stressful. It is also possible that the clinical situation is overwhelming to young people as there are frequently many clinicians (up to seven!) in the room at the same time. Long travel times may also contribute to the stress. Disappointment at clinic outcomes may potentially contribute to the deterioration in mental health following the appointments. Further investigation is required into this area but it is important to reduce any stress provoking factors associated with clinic visits for this cohort of young people.

50% of families express dissatisfaction about the travel to clinic. Many families have to travel for over 3hrs to get to their appointments. This can be costly not only in terms of travel costs, but also means that for parents a full day is needed off work and the young people miss a significant amount of time in school / college. Mermaids' members frequently request local care and this should be considered urgently.

Adult gender identity services have provision for providing additional therapy such as speech therapy, hair removal and occupational therapy [5]. The child and adolescent service has no such provision and no help or advice is offered in this area. Adolescents frequently feel self-conscious about their speaking voice and some refuse to speak to people they do not know as a consequence. They may become withdrawn and non-participatory in school and out of school. Young people often develop musculo-skeletal problems a result of wearing binders or adopting bad posture to hide their anatomical sex characteristics. No advice or help is offered by the GIDS in this area. Parents are left to support their child in these areas by employing private voice coaches and physiotherapists etc. Young people who are beginning medical intervention are told to consider fertility preservation but absolutely no practical help is offered in this area. The same holistic care should be given to adolescents as is offered within adult services.

Puberty blockers are completely reversible. It is the opinion of Mermaids that the wait for these blockers in the present service for those young people who present during puberty is far too long and results in increased feelings of gender dysphoria, increased incidence of self-harm and deteriorating mental health. There is good evidence that prescription of blockers improves mental health and that cross sex hormones decrease gender dysphoria [6]. The risk of suicide is disproportionately high in this group and urgent changes need to be made to waiting times in order to avoid tragedy in the future. Delays in preventing puberty allows development of secondary sex characteristics (eg facial & body hair, voice dropping, development of breasts), that are difficult and costly to reverse in the future and require prolonged treatment to do so. In 2008 Cohen-Kettenis [7] wrote "the child who will live permanently in the desired gender role as an adult may be spared the torment of (full) pubescent development of the "wrong" secondary sex characteristics (e.g., a low voice and male facial features for the ones who will live as women, and breasts and a short stature [males are on average 12 cm taller than women] for the ones who will live as men)". In the same paper Cohen- Kettenis, when writing about consequences of failing to delay puberty, states "It may lead to developmental arrest, and a psychological functioning forever hampered by shame about one's appearance. This implies that "in dubio abstine" may actually be harmful. Realizing the potential harmfulness of non-intervention, one may wonder whether not providing treatment may not only be doubtful on ethical grounds, but also have legal implications". It can easily be argued that delaying treatment for over 12 months will have similar psychological and physical consequences as not treating at all.

Clearly from a psychological and a physical perspective, earlier treatment is advantageous to late treatment. Treatment of inevitable co-morbidities that will arrive from failure to delay puberty undoubtedly increases costs to the NHS (A&E visits, psychiatric support, speech therapy, occupational therapy, cost of avoidable further surgery such as mastectomy, facial feminisation surgery, thyroid chondroplasty, tracheal shave etc,) and has significant negative impact on the final outcome for the individual.

An urgent review of child and adolescent gender identity service provision is required with a fast track pathway for those who present during puberty. The monopoly of service provision needs to be discontinued.

References

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