

“*what do I
do now?*”



The Parents' Future Planning Group

*A book to assist parents upon
hearing that their child has
special needs*

what do I do now...

Compiled and Produced by the Parents' Future Planning Group in 2000
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Finally, I wish to thank the members of the Parents' Future Planning Group, St Michael's House, without whom this booklet could not have been produced.

Note: On March 23rd, 2010, in his speech on the cabinet reshuffle, the Taoiseach indicated that the name of the Department of Social and Family Affairs will be changed to the Department of Social Protection. However, at time of printing the change has not happened and the Cabinet has deferred a decision for a number of weeks. Therefore, in this publication we maintain the old title.

what do I do now?

A booklet to assist parents upon hearing that their child has special needs.

This booklet is written by parents of people with special needs for parents who have just learned that their child has special needs. It is intended to be a personal, supportive and realistic aid in coming to terms with what most parents would describe as a devastating experience. It is more than an information booklet. This is a personal message of encouragement from a group of parents who have vigorously campaigned to ensure that a bright future awaits all children who are born with special needs.

I cannot recall the number of times parents have asked why there is no booklet available that we can refer to for all the information we require once our child is diagnosed as having special needs. We in the Parents' Future Planning Group decided to produce such a booklet. We hope that the information within will be of benefit not only to parents of babies newly diagnosed with special needs, but also to the staff whom the parents meet along the path of their child's life.

Our members were asked to write their thoughts on the topics they felt were most important to them at the time of the child's diagnosis.

These are the views of those parents. Many of these parents used the term "mentally handicapped" instead of other more politically correct terms. There are many reasons for this including the belief of those parents (and the Parents' Future Planning Group and the NPSA) that, at times, politically correct statements were, in some quarters, seen as more important than providing appropriate service to people with intellectual disability.

The producers of this edition felt that it was appropriate to continue to respect the views of the contributors.

We sincerely hope that this publication will help to provide some reassurance for families at a very sensitive time.

We have done our utmost to ensure that all the information in this booklet is correct and up to date but if you feel that we have missed out some piece of information that would have been useful to parents, we would be delighted to hear from you.

Karen Canning. Chairperson PFPG.

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introduction

welcome to Holland!

I am often asked to describe the experience of raising a child with a disability - to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this.....

When you are going to have a baby it is like planning a fabulous vacation trip - to Italy. You buy a bunch of guide books and make your wonderful plans. The Coliseum, the Michaelangelo David, the gondolas in Venice. You may learn some handy phrases in Italian. It is all very exciting.

After months of eager anticipation the day finally arrives. You pack your bags and off you go. Several hours later the plane lands. The stewardess comes in and says "Welcome to Holland!". "HOLLAND!?!!" you say. "What do you mean Holland? I signed up for Italy. I am supposed to be in Italy! All my life I have dreamed of going to Italy." But there has been a change in flight plan. They have landed in Holland and there you must stay.

The important thing is that they have not taken you to a horrible disgusting place full of pestilence, famine and disease. It is just a different place. So you must go out and buy new guide books. And you will learn a whole new language. And you will meet a whole new group of people you never would have met.

It is just a different place. It is slower paced than Italy, less flashy than Italy. But after you have been there a while and you catch your breath, you look around you, and you begin to notice that Holland has tulips, Holland even has Rembrandts. But everyone you know is busy coming and going from Italy, and they are all bragging about what a wonderful time they had there. And for the rest of your life you will say, "Yes, that is where I was supposed to go. That is what I had planned."

And the loss of that will never go away, because the loss of that dream is a significant loss.

But if you spend the rest of your life mourning the fact that you did not get to Italy, you may never be free to enjoy the very special, the very lovely things about Holland.

Emily Pearl

Originally from AFASIC News No. 78, May 1995

feelings

on being told your child has a disability

" I remember thinking we were the first parents in the world ever to have a handicapped child, immediately worrying about what would happen in the future. Once the initial shock had gone we had to get on with the practical things and not be concerned with future plans. At that stage we would not have thought of what effects Denise's birth would have on our son or future family." *Des*

" My recollection is that initially because there were no physical indications that there was anything different I did not believe there could be anything wrong with my daughter. So I failed to understand what this meant. I had a belief that if I concentrated and worked hard with her we would eventually overcome any problems that existed. When it became obvious that I wasn't succeeding my feelings were of frustration, anger, and disappointment which on occasions were directed at my daughter which in turn led to feelings of guilt and self-remorse that I allowed this to happen. Then there was a slow realisation that this was not something I could solve on my own; that help was needed and I thought about how I could best go about this." **Kay**

"When Paul was born his feet were blue. I was worried and asked if anything was wrong. No-one said anything except they told me he was going to special care. That made me feel worse. Later, when my husband came, I thought he looked very shocked. He had been told Paul was handicapped, but he didn't believe it. About an hour later the doctor came and asked if I noticed anything about the baby. I asked why he was so blue. He said he was handicapped. When I asked what type, his answer was that he is mongol and they are all the same. I dreaded going to see him. I thought I might see a monster. But he was lovely, he fed well and was very good." **Patty**

"What would it do to the relationship between myself and my husband? Would our marriage survive this major obstacle? Would our love be strong enough to cope with all the problems Kealan would bring to our family unit? What struck me afterwards was how I thought of us and not the baby. There was a feeling of numbness and sadness." **Karen**

" I did not know that Suzie was handicapped for the first five months. When we had the specialist look at her eventually in Temple Street, I thought that she was only mildly handicapped and would catch up later. For a long time I thought she would catch up with her twin who was normal, but she never did, and we had to accept it. I felt surprised when I learned that Suzie was handicapped, and have always been delighted when she seemed to be making progress. When we were told that Suzie was severely handicapped, we were both a little shocked. Given Suzie's hyperactive condition and love of climbing, I feared that she would not survive into her twenties. Now that she is twenty two, I am delighted that she is still around and regard it as something of a miracle." **Brian**

" Suzie was first born of twins, both girls. We had no idea that Suzie was handicapped but I do remember I was shouting at nurses why she was not crying at birth. Just then she gave a scream and I relaxed. With the two of them and another child under three, it was all systems go. Suddenly I remember feeling when I was feeding her (at three months) that there is something not quite right here. She was not keeping up with her twin. She barely smiled. I said nothing at the time. One day, my husband said there is something about that little one and I cannot put my finger on what. I could feel the fear going through me at this because I knew then, as he noticed, there was definitely something wrong. Next the district nurse gave us the name of a specialist at the hospital. We went to see him. He said he found her too young to say, but by what he could see she was slow. But I knew myself then. My brother-in-law, who is a G.P., was over from the U.K. and said he put her as moderately severe. I was annoyed with him. What did he know? But he was spot on. I remember lifting her in my arms and shook her and said do something for God's sake. She gave me her first beautiful smile. Since then she loves the rough handling, the cuddles etc." **Ann**

" We were numb. My wife was distraught and could not sleep." Jimmy

" When I first saw Paul I knew straight away he was Down's Syndrome but the doctor said wait until they took a blood test. It came back positive after two weeks. But I knew myself as Paul is a twin and there was so much of a difference. The hospital did not say straight away. I think they were letting me get used to it first. I think they should tell you right out. As he was needing a lot of care, we did not have time to think about his handicap." **Rose**

" We discovered that Helen was handicapped when she was a year old. By the time we were told, at one level we had some notion that something was wrong. At another level it came as a complete shock. My feelings were a combination of numbness and thinking that I had to help Maureen. There was no sense that anything had changed in our attitude to Helen, as the child we had known the day before we were told was the same child as the one we knew the day after we were told." **Seamus**

" Thinking back now - I think the only feelings I had were of numbness and disbelief. I didn't know anyone my own age with an intellectually disabled child. I didn't know much about her handicap - all I did know was that she cried a lot, was very difficult to handle and that she wasn't like my other children." **Maureen**

" Do not try to put a brave face on situations. Let people know how you feel and take any offer of help you get. You won't get too many! Do not think that you have to be superwoman or superman." **Mary**



steps

to take upon hearing the news

" Speak to other parents of children with mental handicap. It doesn't matter which condition the child has, as the emotions parents have are the same on diagnosis of their child's mental handicap. Those parents have been there before and are a mine of information." *Patty*

- " Find out as much information as possible about:
- your child's condition
 - the service provider in your area and what service it will provide to meet your child's needs (these are State funded services). These include Early Services, Developmental Day Centres, Schools, and Transportation. A social worker will provide the necessary information. Parents groups are another good source of information.
 - entitlements: grants (e.g. house extensions), nappies, medical card, long term illness book, Disability Allowance, Respite grant, car adaptations.
 - Clinicians you are likely to meet with your child: consultant paediatrician, neurologist (paediatric), physiotherapist, occupational therapist, paediatrician (from the service provider), social worker, psychologist, speech therapist." **Karen**
- " Ask your doctor for confirmation about the particular handicap and ask relevant staff as to what steps you should take. I do not think it is advisable in the immediate aftermath of the birth to get bogged down with too much information. I would advise parents to wait a couple of weeks and then seek the information. If, for example, the child has Down's Syndrome, seek help from the Down's Syndrome Association. Check if there is an association dealing with your own child's particular handicap." **Rose**
- " Quickly try to come to terms with the situation and approach it in a constructive, rational and productive manner. Seek out the various facilities, organisations and practical services that exist. Try to establish the extent of the problem - through assessment etc. Discuss the problem and possible remedies with other parents that have experience and dealt with their own situations." **Des**
- " It might be advisable to look for a second opinion, and ask if there is anything that one can do to help. It was difficult to get information with regards to our daughter's illness as it was a rare condition associated with the 15th chromosome. The people we consulted did not know a great deal about the condition. One doctor I asked told me that our daughter had 'atrophy in both hemispheres' and that was about it." **Brian**
- " If you are unhappy and you need clarification get a second opinion. However, mothers usually have a sense if something is not quite right. She should go all out to get all the answers to questions she may have." **Ann**

- " Get in touch with your local service provider (there is one in your area)) and check out other services to find out what services are most suitable to your child."
Beatrice
- " Read up all about the handicap to be familiar with it and to help the child to make as much progress as possible. Treat the child as you would your other children or as normal as possible." *Ena*
- " Get advice from a professional body or otherwise which is experienced in dealing with intellectually disabled children." *Kay*
- " They should share their problem with as many people as possible. With the benefit of hindsight I feel we tended to try to solve our own problems, which kept us pretty busy and kept us away from friends. I wonder now if some would have liked to help." *Seamus*
- " The first thing I think parents should do is to get as much information about the child's handicap as possible. Second, get in touch with the local service provider in their area and get enrolled in their system. Third, join a parents' support group - being with other parents and sharing problems does help." *Maureen*
- " Seek help and advice from people you trust - share your feelings. Contact the appropriate association for help and guidance - learn from the experience of others." *Arthur*
- " They should seek as much information as they can. Also, physiotherapy is very important as soon as possible." *Jimmy*

dealing

with the professionals

" I would ask the doctor/consultant to explain the handicap fully (in layman's language) - how it happens, what stage our child is at now and what the normal pattern of development is for this particular handicap. If he/she cannot give me adequate information, can they recommend someone else." **Maureen**

- " Generally speaking, my experience with the professional people of various disciplines was a good one. As a consequence, there are no great changes I would have made given the benefit of hindsight. However, in both my experience and in discussions with other parents there are some cases where there is a problem with attitudes - professional people tend to adopt a "we know best" syndrome. Often, while appearing to listen to the parents view, they do not pay too much heed to what we have to say." **Patty**
- " Just shout for what you want." **Jimmy**
- " Remember YOU are the expert concerning your child, not the professionals. But we do not have all the answers as this is a new situation for parents of children with an intellectual disability and sometimes we need guidance and information and some hope for the future i.e. will my child walk, talk, go to a normal school?"
Karen
- " It would have been better to know in advance what doctors and clinicians we would meet along the way." **Kay**
- " Considering we were completely ignorant about Down's Syndrome I would ask the professionals to explain about the condition. If this was not forthcoming, I would ask them to put me in touch with the people who could help. I have long since held the view that these types of discussions are avoided by the professionals in maternity hospitals. In coming to this conclusion, it must be taken into consideration the mental state of both of the parents of the new born child." **Rose**
- " Looking back, I think my wife and I were too accepting and grateful for the help we received. I feel now that we should have pushed and questioned more. I feel that there could have been greater liaison between home and care. At one time it looked as if Suzie would speak and be out of nappies. We were assured that these things would happen when the time was right. Twenty two years later we are still waiting. I feel that if we knew exactly what had been happening to Sue when she was at her day-care unit and they knew what was happening at home, we might have devised a training programme between us. It is possible that such co-operation now exists, but it has always been difficult to obtain specific details. Now that Sue is out of her teens, her patterns may be so engrained that there is little that can be done." **Brian**

- " I feel looking back there were openings in Suzie's mind which could have been worked on. For instance, I was taking paint off a table one day (she was almost 5-6 yrs. at this stage). I was using sand paper. Suddenly Suzie picked up a piece of sandpaper I had discarded and started to rub the table. My father was alive then and said, "you know there is an opening there for improvement." I mentioned it to the occupational therapist at the time and I was disappointed with her reaction. She felt it was nothing much. I was angry. But obviously even she knew very little at this stage. So we lost it. If I had to do it again I would have shown my hurt and anger. Maybe I would have got some action." **Ann**
- " We would have been more assertive and asked more searching questions. The specialists tried to make the most hopeful diagnosis for our child and because we had no experience of intellectual disability we took their word." **Des**
- " I would ask more questions about his syndrome and make sure his abilities were brought out in full so as he could have a good quality of life." **Beatrice**
- " I would abandon the "thank you, thank you" approach and would regard them as people who were accountable to us and would insist on that accountability. Incidentally, this does not mean that I would be aggressive but instead, would be clear in my expectations of them and equally clear if they were not meeting these expectations. I think it is more difficult for a younger person to be successful in doing this because it seems to me that some professionals are influenced by age and grey hair and possibly even the profession of the parents. Nevertheless, young people should try to present them with a clear informed expectation of their co-operation." **Seamus**
- " We saw many paediatricians and consultants before we had a diagnosis for Niall. Each of them told us a different story and it was like a roller coaster of emotions between hope that Niall would be O.K. and "grow out of it" to being told that he would probably not live past his second birthday. Niall is now thirteen! You need to gather all your courage and question everything again and again. Trust your instincts-always." **Mary**

- " If possible, bring someone with you on your visits to consultants, hospitals and clinics so that you don't have to remember everything that is said yourself. Also, get a letter outlining what has been done and the results of tests etc. as it is very hard to remember names and terms that medical staff sometimes use." **Mary**
- " In hindsight, we probably would have been more insistent on answers and information. However, their training in relation to "human contact and relations" was clearly at the time almost non-existent. What I am saying is that it would not have made any difference at the time how I dealt with them, in view of their lack of concern and inability to show care and attention to our needs. Hopefully this has improved these days!" **Arthur**



telling

*other people/relatives
that your child has
special needs*

" I would advise parents to meet the issue head on. Call a family get-together inclusive of the extended family. Explain the situation. Look for their understanding and support, including their own children. As members of the family, try to instil a collective responsibility to share the problems that may arise in a caring way. Request that they treat the child in as normal a way as possible and include the child as part of the family in the same way they would expect their own children to be treated." *Patty*

- " I told everyone from Day 1. Meet as many parents in the same situation as you can. It is the best therapy for yourself." **Beatrice**
- " I think family and friends should be told immediately and to bear in mind that this might be the first time that family have been confronted by this sort of news. I think this type of situation will help others to first of all think a child has been born and the handicap is secondary. This will help the parents not to feel isolated and alone. We adopted this attitude in our own situation and we found it worked very well." **Des**
- " Tell them the truth in as far as that is possible. We have never tried to hide the fact and I bring Suzie out for a walk at least once a day if it is possible. I find that friends, relatives and neighbours have always been reasonably understanding and we try not to inconvenience them by allowing Suzie to run riot in their homes." **Brian**
- " Be totally honest. It is not anyone's fault. Most people understand and those that don't, forget them. It is you who has to cope, not them." **Ann**
- " We would advise parents to tell only the immediate family initially, including our own mothers or fathers and sisters and brothers." **Kay**
- " Tell them straight away and do not be ashamed. No-one knows when it could happen to them." **Jimmy**
- " Tell relatives and friends immediately. They will give you the emotional support you need." **Kay**
- " Tell the whole world straight away. Give as much information as possible and don't be too brave." **Seamus**
- " There is no easy way - everybody should be told (giving them as much information as you have) and as soon as possible. The handicap should be spoken about - not ignored. Other people are embarrassed to mention it unless the parents bring it up." **Maureen**



addressing *the needs of the other* *children in the family*

"Try to treat the situation normally by including the disabled child in everyday family life. Ensure that the other children get their fair share of time and attention. Recognise that their needs are just as important." ***Jimmy***

- " Try to give siblings a lot of time which is quite hard as a handicapped child needs so much. You can only do your best." **Patty**
- " This advice would depend on where the child with the intellectual disability comes in the family i.e. eldest, middle or youngest.
Eldest: the subsequent children do not know any different as the child with intellectual disability is there already. Beware of younger siblings copying the inappropriate behaviour of the intellectually disabled child.
Middle/Younger: Rules are different for the child with intellectual disability."
Karen
- " Explain about the handicapped child as soon as the other children can understand. Impress upon them that the child will need to be stimulated as much as possible. But in doing these things, try to explain that they can have their own hobbies and interests. And make the effort to bring them to whatever activities they might decide to do." **Des**
- " I would advise them to encourage the siblings to help with the handicapped child and to treat the child as normally as possible. However, it is important not to expect too much from them." **Brian**
- " Get all siblings involved. Suzie has two older sisters and a brother as well as her twin. The two older ones are wed and have left home. Her brother loves her but is short fused and impatient. So I would think twice about putting any pressure on him although he would take her for a walk in the park. Her twin baby-sits if I want to go somewhere special. I don't make a habit of it. They are 22 now." **Ann**
- " We would advise parents to encourage their own children to give the new brother or sister plenty of love. The parents should show the same level of love to the other children. Some kind of residential and/or respite care in the early years might give parents and siblings a chance to come to terms with their changed circumstances." **Kay**
- " Let them be involved in helping as you would when a new baby is born but not have them feel they have to do things for the handicapped sibling. Try not to leave your other children out. This can happen as everything tends to revolve around your special son or daughter as they can need a lot more care." **Mary**
- " The same attitude should apply to all the children." **Beatrice**

- " This is very difficult. As mentioned before we tended to take the full burden and did not ask anyone for much, including the children. The result is that they have very little involvement in her care except for "sitting". I feel that if we had asked them to just occasionally take her with them when they were going out with their friends it might have been good for them and her. It would also have given us more energy to devote to them. The only other advice I would give would be to try to care for the other children as much as your energy will allow. After that do not feel any conscience about missed opportunities. If a child feels loved they can cope without the frills as long as they understand why they don't have them." *Seamus*
- " It is a very difficult thing to do when you have a handicapped child but ideally all the children should be treated equally. If you have children older than the intellectually disabled child, encourage them to play with and care for the handicapped child as they would do for a normal younger child. When the intellectually disabled child is the eldest, the younger children will soon pass them in development and I think the same rule applies, treat him as normally as possible." *Maureen*
- " Give them the same loving attentions as you give your special child. Treat them as equals. Allow them and encourage them to care for their brother/sister. Make sure that they fully understand the needs of that special child. Give them time to develop their own relationship in their own way. If love is already nurtured and taught in the home then there will not be a problem." *Peggy*



allowing yourself to grieve

"Based on the fact that life continued pretty much the same for me - I was a working wife with another young child to take care of with all the usual everyday problems, I don't believe I actually had time to grieve. My daughter fitted in with family life and any extra requirements specific to her just became a way of life. Therefore, my advice to parents of a recently diagnosed child is treat the situation as normally as possible. Quickly learn to accept the reality that the problems will not go away. Concentrate on the positive side and provide the extra care and attention that is required to help their child lead as happy a life as possible." **Kay**

- " I only grieved for what he would not be able to do as an adult. But he has turned out much better than I ever hoped for." **Patty**
- " It is like a bereavement because you have lost the child you thought you were carrying; the child whose life you had planned.
One needs support from: spouse/partner (remember they are grieving too), family, close friends, neighbours.
Realise that people do not know the right thing to say and it all comes out wrong. You will hear comments such as "God's gift", "Cross to fit the back", "God's plan", "You were sent the child for a reason" etc., etc.
The grief does not stop for some parents. There is a bereavement cycle which goes something like the following: Denial-Grief-Blame-Anger-Bargaining-Hope-Acceptance. I did not understand my feelings at the time- being so sad and fearful for months and then angry for years.
I feel sadness at birthdays, Christmas, First Communion etc., when you think of what stage the child should be at." **Karen**
- " We were filled with an overwhelming sense of sadness. Sadness in the sense that you can see the things that the child will not be able to do. And I think in that way the personal grief is secondary. This is not to say that every parent would feel that way. I think it would be wise to remember the child is first, the handicap second." **Jimmy**
- " I never grieved for Suzie, though I was naturally sorry that she did not have the same opportunities that a normal child would have, and that she has missed out on so much. But Suzie seems a happy child and we have done what we could for her. I do not begin to know how to advise others, but if they can accept the child as it is, make the best of it, and try to improve the child's condition in any way possible, that is the best you can do. Try not to think of yourself but of the child. However, it is easy to write that." **Brian**
- " I had feelings of fear when Brian came out and said he felt something was not right. I accepted it and was so busy I had little time to think. I think the new parent, if it is their first child, will be devastated and question everything; even the existence of God at times. But it will pass and they will get on with the job God gave them." **Ann**

- " There were no kind of opportunities. When our child was born in 1974, grieving was not really encouraged. Counselling services now exist and I think grieving parents should avail of these. Try to accept the child as you accepted your other children. In the end you have to." **Des**
- " We did not have time to grieve as our son took up a lot of time. He was sick quite a lot when small so we just were glad when he was better." Rose
- " Be very open about it in particular with your relations and caring friends." **Beatrice**
- " We had no chance to grieve. The only advice I could give is to get away together as much as possible." **Seamus**
- " When my child was young we were involved in a parents support group for a short while. While I enjoyed the group meetings I didn't consider that it was grief counselling. If there is counselling available, I would recommend it for parents." **Maureen**



entitlements

This section lists the allowances and benefits to which families of children with special needs are entitled.

- 1 Domiciliary Care Allowance - monthly payment to parents of children under 16 years of age once the child's intellectual disability has been diagnosed. Allocation decisions are based on need
Apply to Dept of Social & Family Affairs (see 'note' on page 2).
- 2 Respite Care Grant - annual grant given to parents in receipt of Domiciliary Care Allowance and Carers Allowance (only 1 grant per family/year).
Apply to the Department of Social and Family Affairs (see 'note' on page 2).
- 3 Long Term Illness Book - entitles child to free medication associated with illness. e.g. Epilepsy, Diabetes. *Apply to your local HSE.*
- 4 Nappies (2-4 day) - from aged 2.
Apply to your local HSE.
- 5 Incapacitated Child Tax Allowance - *contact your income tax office.*
- 6 Carer's Allowance (means tested) for parents looking after their child full time. - *Apply to Dept of Social & Family Affairs (see 'note' on page 2).* Carer also entitled to Free Companion Travel Pass, Telephone rental, TV Licence, Gas, Electricity.
- 7 Exemptions/Refunds for Disabled Passengers/Drivers - Severely disabled persons who use a specially adapted motor vehicle as passengers & who meet certain criteria are entitled to:
 - exemption from motor tax & refund/exemption from Vehicle Registration Tax.
 - refund of VAT on vehicle & adaptations e.g. swivel seat, ramps, harnesses etc.
 - refund of duty paid on petrol/diesel (up to 600 gallons a year).*Apply to: Local HSE for Primary Health Certificate & then to Disabled Drivers Section, Central Repayments Office, Office of the Revenue Commissioners, Coolshanagh, Co. Monaghan.*
- 8 Disabled Person's Parking Card - applies to disabled person, not adapted car. The card only applies to public car parking areas (disc and pay & display parking). *Apply to The Irish Wheelchair Association, Blackheath Drive, Clontarf, Dublin 3.*

- 9 Mobility Allowance (applicants should be over 16 & under 66 yrs) provides financial support to severely disabled persons (who are unable to walk or use public transport) in order to finance the occasional taxi journey.
Apply to local HSE.
- 10 Motorised Transport Grant
To provide financial assistance to disabled persons who may need a car to obtain/retain employment.
To provide financial assistance to disabled persons who are living in very isolated circumstances & have serious transport problems.
- 11 East Link Bridge - cars displaying disabled passenger/driver card are exempt from toll charge. West Link Bridge - Disabled drivers only are exempt from toll charges That is, the car must be registered as the car of a disabled driver
- 12 Wheelchairs/buggies - *Apply to local HSE.*
- 13 Special orthopaedic footwear supplied if required. Physiotherapist will advise.
- 14 Free spectacle prescription lenses. *Apply to local HSE.*
- 15 Refund of VAT on special equipment purchased, i.e. bed-sides.
Apply to Office of the Revenue Commissioners.
- 16 Disability Allowance - for persons over 16 yrs.
Apply to Dept of Social & Family Affairs (see 'note' on page 2).
- 17 Free Travel Pass and Companion Travel Pass.
- 18 Blind Person Pension - for persons over 18 yrs. (Means tested)
Apply to Dept. of Social & Family Affairs (see 'note' on page 2).

- 19 Blind Welfare Allowance - (means tested) persons 16 - 18 yrs in receipt of Disability Allowance may be entitled to a small allowance. Blind people over 18 yrs who are receiving Blind Person's Pension may be eligible.
Apply to Dept. of Social & Family Affairs (see 'note' on page 2).

- 20 Medical Card - for persons over 16 yrs. (Means tested).
Apply to local HSE.
(The young adult is means tested not the carer).

- 21 Grant for adaption / extension of house to facilitate disabled person.
Apply to local County Council.

All the above grants and allowances are subject to change with each annual budget.

rights

People with a disability have social and economic rights. Uniquely among other citizens, they lack the voice and the means to lobby for the resources needed to give meaningful expression to those rights. They cannot overcome the barriers alone.

Therefore the National Parents' and Siblings' Alliance (NPSA) has established this Charter of Rights and will be campaigning to enshrine these rights in Ireland's Constitution to secure a future for all children with special needs.

It is hoped that this Charter will inform all parents of the minimum standards required for the well-being of their children.

NPSA Charter of Rights

People with intellectual disabilities and/or autism have:

1. a right to live and be recognised as independent people with the freedom to enjoy, in a caring and loving environment, their civil, economic and social rights in equity with all other people, regardless of age, gender or disability;
2. a right to resources and support [from the State] appropriate to the needs of the individual and in this context:
 - 2.1. a right to a detailed assessment of their needs and to comprehensive, individualised (self directed where appropriate) medical, social and living support;
 - 2.2. a right to an appropriate education geared to their potential and abilities;
 - 2.3. a right to training and/or further education;
 - 2.4. a right to rewarding and satisfying employment where appropriate;
3. a right to be free from discrimination and from economic, sexual, or other forms of exploitation;
4. a right to cast their vote or have their vote cast by their legal guardian or carer;

People with intellectual disabilities and autism, their parents, guardians and siblings have:

5. a right to participation and consultation in the formulation and implementation of all policies which affect their lives;
6. a right to select and determine, in consultation with service providers and professionals, in a timely and planned manner, the support services and infrastructures they require;
7. a right to participation in the governance and direction of all service organisations charged with the provision of support services, including all statutory agencies;

The parents, guardians and siblings of people with disabilities and autism have:

8. a right to information and consultation about the needs of their family member, irrespective of age and where appropriate to be heard and their wishes acted upon;
9. a right to counselling, support and respite care when needed;
10. a right to respect, recognition and compensation for the roles they play;



behaviour

management

guidelines

Outlined are twelve basic principles which were written by two psychologists from St. Michael's House and which the Parents Future Planning Group would endorse. If parents can apply these principles having ensured that there are no medical reasons which might be the cause of particular behaviours which their child may present with, they will be taking a significant step towards being more in control of the family situation, and, ultimately, a more harmonious household.

1. Consistency is the key to success. Parents, grandparents, other adults and children need to have one consistent approach when dealing with the special child. Problems arise when one person "spoils" the child while others try to apply rules consistently.
2. Treat your disabled child the same as the rest of the family. The same rules should apply across the board. It is not necessary to make concessions for the disabled child other than making allowances for the slower development of some skills.
3. Good planning avoids problems. Think ahead about any potential problems that might be encountered and make plans to avoid them where possible. For example, if shopping is an activity your child does not like, try to plan your routine so that you do not have to bring them.
4. Work first, then play, ALWAYS. If there is only one rule applied in your household, this should be it. For example "You can play with your toys after you help clear the table". Avoid giving treats to keep a child quiet. Give treats as a reward after behaviour has been good.
5. Catch your child being good and ignore bad behaviour. Your attention should be focused on recognising good behaviour. For the most part, ignore minor misbehaviours.
6. Set clear limits. Very clear rules and guidelines are needed, not only for your disabled child, but all children. Avoid being overly sympathetic or protective to your disabled child.
7. Always expect a little more from your disabled child. Low expectations will prevent them from reaching their true potential. Because it is that much harder for the disabled child to make progress is all the more reason to push for that extra effort. Similarly, parents must develop an intolerance for difficult or challenging behaviour. Some parents tend to accept bad behaviour as part of the disability but this is rarely the case.

8. Avoid letting the child see you angry. Being annoyed and frustrated by your child's behaviour is perfectly understandable but if you let them see this they are more likely to repeat the problem behaviour.
9. View bad or difficult behaviour as an opportunity to learn. The worst experiences are the ones we prefer to forget, but do not do so. Instead, review what happened and make plans so that the same problem does not arise again.
10. There is no such thing as a perfect parent. Parents are generally very hard on themselves. When there is a disabled child to look after they push themselves even harder. Do not try to do it all alone. Take help wherever you can get it. Do not pretend you can manage when you do not feel you can. It may seem like unrealistic advice, but you do need to stop thinking about the child and pamper yourself sometimes.
11. Keep in touch with your unit, clinic and other parents. One of the greatest revelations to parents upon chatting to other parents is "I thought I was the only one with these feelings". You are not alone on the emotional roller coaster that is raising a child with special needs. You are not the only one who encounters temper tantrums, who feels like screaming or who wonders how it will all work out in the end. But you may be someone who is doing this alone. Regular contacts with the support services and other parents can relieve a huge burden for parents. If you are encountering a problem with the child at home, get help. Talk to a staff member or ask to meet a psychologist. Seek whatever assistance is necessary. Compare notes with other parents and you will be amazed how understanding and helpful they can all be.
12. You can make a difference to your child's behaviour. You can make a difference in how your child behaves. Do not accept bad behaviour as part of the child's condition. Seek advice, read the materials and set clear and reasonable goals for your child.

- 
- *some of the people you might meet along the way*
 - *service providers*

HOSPITAL

Midwife,
Obstetrician,
Paediatrician,
Paediatric Neurologist.
Geneticist,
Metabolic Consultant,

HOME

G.P,
Practice Nurse
Public Health Nurse,
HSE Doctor,

SERVICE PROVIDER

Consultant Paediatrician,
Physiotherapist,
Occupational therapist,
Speech therapist,
Social worker,
Home worker,
Dietician,
Psychologist,
Drivers on bus to unit/school

Bus Escorts,
Teachers,
Special Needs Assistants
Special Educational Needs Organisers
(SENOs)
Resource teachers
Care workers,
Registered Intellectual Disability Nurses,
Other Parents.

Service providers are paid by the State to provide a service for our children with special needs. They are not state run charities. Families should not feel indebted for whatever service their child receives. Your child is a citizen of the State and therefore entitled to all services that the state provides. We are consumers of a service which is sponsored by the State.

The ideal way in which the various services should come on stream is as follows:

- When a child is diagnosed with special needs soon after birth, the hospital should put the parents in touch with their local service provider.
- Contact with home based services should be effected as soon as possible where parents will receive valuable information and support.
- The child’s needs should be assessed by a doctor, physiotherapist, occupational therapist, speech therapist and psychologist and a programme drawn up for the child.
- The child should also be assessed under the Disability Act 2005. Information on the assessment procedures may be obtained from your local health office.
- There should be regular assessments thereafter (perhaps on a yearly basis) and services put in place to meet those needs.

Early services: 0 - 4 years.

- Social worker arranges introductory sessions where mothers & babies/young children get to meet each other.
- Paediatrician also available.
- Physiotherapy, occupational and speech therapy classes for the child if required. (This includes LAMH and Hannon communication courses)
- Home teacher and other home based services available as required.
- ‘Preparation for school’ talks, when the child is approaching school going age.

The child generally moves from the early services at between 4 and 5 years of age to the educational services, which includes attendance at special schools, Child Education and Day Development Centres (DDC) or integration into mainstream schools. The child’s needs and parents’ preferences will determine the type of educational services which the child attends. Children remain in the educational services until they are 18 years of age. During this period, children with special needs continue to receive health related support services from either the specialist service providers or the HSEs.

At around age 18 they should move onto the adult services; these include:

1. Vocational Training Centres.
2. Day centres providing a range of activities for persons with high dependency needs.
3. Sheltered employment: provide both therapeutic and low-level vocational training.
4. Supported and Open Employment: adults work in the community. It is possible your child could avail of a combination of these services.

Respite Care: This support service provides families with the opportunity for “time out” for both the parents and other siblings and also helps the child to develop a level of independence and prepares them for living away from home. It can be provided in a residence managed by a service provider or with a family through various schemes. There are also non-residential respite schemes; these vary from service to service.

Residential Care: At present residential care is often provided when parents can no longer care for their child at home. However, it should be a natural progression for our children with special needs and should be provided on a planned rather than a crisis basis and be facilitated by the opportunity for the child to have developed a level of independence through the use of the respite services. It is currently provided in either community or residential centre based services, with the child or adult living with other people with similar needs and cared for by staff. However, there are advocates who say that many people would have a better quality of life if they were supported to live independently.

Currently the Health Information and Quality Authority (HIQA) have developed Standards on residential care which are being operated on a voluntary basis by some service providers.

Decision Making: Management and staff should encourage parent and family involvement in all decisions about their child.

We would advise that parents become involved in parent groups associated with their service provider. It is vital that clear communication exists between parents, professionals, frontline staff and management at all times.



telephone numbers

Relevant Numbers

Some Disabilities you Might Hear About

Service Provision Organisations

Citizens Information Board

DISABLED DRIVERS SECTION

Central Repayments Office,
Office of the Revenue Commissioners,
Coolshannagh,
Co. Monaghan.
Ph: 047 82800

FEDERATION OF VOLUNTARY BODIES

Oranmore Business Park,
Galway.
Ph: 091 792 316
Fax: 091 792 317
www.fedvol.ie

IRISH WHEELCHAIR ASSOCIATION

Blackheath Drive,
Clontarf,
Dublin 3.
Ph: 01 833 8341
www.iwa.ie

HEALTH INFORMATION AND QUALITY AUTHORITY (HIQA)

Dublin Regional Office, Smithfield,
George's Court,
Georges Lane,
Dublin 7
Ph: 01 814 7400
Email: info@hiqa.ie
www.hiqa.ie

INCLUSION IRELAND

Unit C2,
The Steelworks,
Foley St.,
Dublin 1.
Ph: 01 855 9891.
Fax: 01 855 9904.
Email: info@inclusionireland.ie
www.inclusionireland.ie

NATIONAL PARENTS & SIBLINGS ALLIANCE (NPSA)

31 Magenta Hall,
Santry,
Dublin 9.
Ph: 01 862 4100
Email: npsa@eircom.net
www.npsa.ie

NATIONAL COUNCIL FOR SPECIAL EDUCATION

1-2 Mill Street,
Trim
Co. Meath
Ph: 046 948 6400
www.ncse.ie

HIQA

Head Office,
Unit 1301,
City Gate,
Mahon,
Cork
Ph: 021 240 9300
Email: info@hiqa.ie
www.hiqa.ie

SOME DISABILITIES YOU MIGHT HEAR ABOUT

ANGLEMAN SYNDROME

ASBERGER SYNDROME

ATTENTION DEFICIT HYPERACTIVITY DISORDER (ADHD)

AUTISM

CEREBRAL PALSY

CORNELIA DE LANG SYNDROME

CRI DU CHAT SYNDROME

DOWN SYNDROME

EDWARD'S SYNDROME

FRAGILE X SYNDROME

LENNOX-GASTAUT SYNDROME

NEUROFIBROMATOSIS

PATAU'S SYNDROME

PRADER-WILLI SYNDROME

RETT SYNDROME

RUBINSTEN TAYBI SYNDROME

SOTOS SYNDROME

TRISOMY – 18

TOURETTE SYNDROME

WILLIAMS SYNDROME

WEST SYNDROME

WOLF HIRSCHHORN SYNDROME

SERVICE PROVISION ORGANISATIONS

CARLOW

Delta Centre – South Eastern HSE
Strawhall, Carlow
Tel: 0503-45327

CAVAN

Drumlin House
Cootehill, Co Cavan Tel: 049-5552605
Holy Family Special School & Special
Care Unit Cootehill, Co Cavan
Tel: 049-5552257

CLARE

Clare Federation for Intellectually
disabled Children St Clare's Special
School
Ennis, Co Clare
Tel: 065-6821899

CORK

Brothers of Charity Services –
Southern Services Glanmire, Co Cork
Tel: 021 -821012

Charleville & District Association for
the Handicapped Charleville, Co Cork
Tel: 063-81204

CoAction West Cork
Bantry
Co Cork
Tel: 027-50114

Cope Foundation Montenotte,
Cork
Tel: 021 -507131

L'arche Ireland
Togher Road, Cork
Tel: 021 -31 8880

St Patrick's
Innishannon, Co Cork Tel: 021-775202

DONEGAL

Coiste Cuchulinn
Falcarragh, Letterkenny, Co Donegal
Tel: 074-65345

James Connolly Hospital Ltd
Carndonagh, Co Donegal
Tel: 077-74206

Little Angels Association
Ballyraine, Letterkenny,
Co Donegal
Tel: 074-221 64

DUBLIN CITY & COUNTY

Central Remedial Clinic, Clontarf,
Dublin 3. Tel: 01-8332206

Cheeverstown House Templeogue,
Dublin 6W Tel: 01-4904681

Children's Sunshine Home Foxrock,
Dublin 18
Tel: 01-2893151

Daughters of Charity – Holy Angels
Glenmaroon, Chapelizod, Dublin 20
Tel: 01-8216166

Daughters of Charity –
St Joseph’s Hospital Clonsilla,
Dublin 15
Tel: 01-8217177

Daughters of Charity – St Rosalie’s
Convent Lane, Portmarnock, Co Dublin
Tel: 01-8460132

Daughters of Charity – St Teresa’s
Temple Hill, Blackrock, Co Dublin
Tel: 01-2882280

Daughters of Charity Services
Navan Road, Dublin 7
Tel: 01-8385535

Down Syndrome Ireland
Citylink Business Park,
Old Naas Road,
Dublin 12
Tel: 01-426 6500

Prosper Fingal
Strand Street, Skerries,
Co. Dublin
Tel: 01-8490915

Good Counsel Centre for the
Intellectually disabled – HSE
Rathfarnham, Dublin 16
Tel: 01-4900074

Hospitaller Order of St John of God –
Carmona Services Dunmore House,
Dun Laoghaire, Co Dublin
Tel: 01-2852900

Hospitaller Order of St John of God –
Menni Services Islandbridge, Dublin 8
Tel: 01-6774022

Hospitaller Order of St John of God –
St Raphael’s Celbridge, Co Kildare
Tel: 01-6288161

Hospitaller Order of St John of God –
Step Enterprises Sandyford Industrial
Estate, Dublin 18
Tel: 01-2952379

Irish Society for Autism
16/17 Lr O’Connell St, Dublin 1
Tel: 01-8744684

L’arche Dublin, Baldoyle,
Dublin 13
Tel: 01-8394356

National Federation of Arch Clubs
Dublin 16
Tel: 01-2951081

Peamount Hospital Newcastle,
Co Dublin
Tel: 01-6280685

Scoil Chiarain
Glasnevin, Dublin 11
Tel: 01-8370622

Sisters of Charity – St Margaret’s Centre
Donnybrook,
Dublin 4
Tel: 01-2603630

Special Olympics Ireland
4th Floor, Park House
North Circular Road, Dublin 7
Tel: 01-8823972

St Joseph's Special School,
Tallaght, Dublin 24
Tel: 01-4515961

St Michael's House Ballymun,
Dublin 9
Tel: 01-8840200

St Paul's Special School
Beaumont, Dublin 9
Tel: 01-8369630

Stewart's Hospital Services Ltd
Palmerstown, Dublin 20.
Tel: 01-6264444

Walkinstown Association for the
Handicapped
Long Mile Road, Dublin 12
Tel: 01-4518759

GALWAY

Brothers of Charity Services –
John Paul II Centre Ballybane, Galway
Tel: 091-755161

Brothers of Charity Services –
Ionad Bruach na Mara Conamara,
Co na Gaillimhe
Tel: 091-572145

Brothers of Charity Services – Western
Regional Services Renmore, Galway
Tel: 091-755241

Galway Co Association for Intellectually
Disabled Children
Quay St, Galway
Tel: 091 -567291

KERRY

Hospitaller Order of St John of God –
Breannan Enterprises
Tralee, Co Kerry
Tel: 066-7122911

Kerry Parents and Friends Association
Killarney, Co Kerry
Tel: 064-32742

St Mary of the Angels Killarney,
Co Kerry
Tel: 064-44133

KILDARE

Ashling House – Eastern HSE
Contact: EHB – Tel: 6289745

Camphill Community –
Dunshane House
Brannockstown, Co. Kildare
Tel: 045-483628

Camphill Community – Kilcullen
Tel: 045-481597

Dara Residential Services
Dara Court, Celbridge, Co Kildare
Tel: 01-6271484

K.A.R.E. (Kildare Association of
Parents & Friends of Handicapped
People) Newbridge, Co Kildare
Tel: 045-431544

Sisters of Charity of Jesus and Mary –
Moore Abbey
Monasterevan, Co Kildare
Tel: 045-525327

KILKENNY

Camphill Community – Ballytobin
Callan, Co Kilkenny
Tel: 056-25114

Camphill Community – Kyle Callan,
Co Kilkenny
Tel: 056-25737

Camphill Community – Thomastown
Thomastown, Co Kilkenny
Tel: 056-54132

Kilkenny Association for Severely
Intellectually Disabled Adults
College Gardens, Kilkenny
Tel: 056-63211

L'arche Kilkenny Community Callan,
Co Kilkenny
Tel: 056-25628

Sisters of Charity – St Patrick's
Kells Road, Kilkenny
Tel: 056-22170

S.O.S Kilkenny Ltd
Callan Road, Kilkenny
Tel: 056-64000

LAOIS

Kolbe Centre
Portlaoise, Co Laois
Tel: 0502-20329

Daughters of Charity –
St Vincent's Centre
Lisnagrç Co Limerick
Tel: 061-339399

LONGFORD

St Christopher's Services, Longford
Tel: 043-41769

LOUTH

Hospitaller Order of St John of God –
Domus Services
Drumcar House, Dunleer, Co Louth
Tel: 041-6851211

Hospitaller Order of St John of God –
Drumcar Park Enterprise
Drumcar, Dunleer, Co Louth
Tel: 041-6851112

Hospitaller Order of St John of God –
Hilltop Services
Ardee Rd, Dundalk, Co Louth
Tel: 042-9334663

Hospitaller Order of St John of God –
North East Services
St Mary's Drumcar, Dunleer, Co Louth
Tel: 041-6851211

N.E.H.B – Mounthamilton House
Regional Austistic Service
Dundalk, Co Louth
Tel: 042-9336217

Order of Malta Enterprises Drogheda,
Co Louth
Tel: 041-9836145

LIMERICK

Brothers of Charity Services – Limerick
Bawnmore, Limerick
Tel: 061-412288

MAYO

Aras Attracta – Western HSE Swinford,
Co Mayo
Tel: 094-51900

Western Care Association Castlebar,
Co Mayo
Tel: 094-25133

MEATH

Meath Sheltered Workshop Ltd Navan,
Co Meath
Tel: 046-29883

N.E.H.B. – Special Care Unit Navan,
Co. Meath
Tel: 046-71647

St Oliver’s Centre Navan, Co Meath
Tel: 046-22079

MONAGHAN

Association of Parents and Friends of
the Intellectually disabled
Carrickmacross Co Ltd
Tel: 042-9663958

Camphill Community – Ballybay
Ballybay, Co Monaghan
Tel: 042-9741939

Clogher House Training Centre
Rooskey, Monaghan
Tel: 047-84768

OFFALY

Offaly Association for the Intellectually
Disabled, Syngfield, Birr, Co Offaly
Tel: 0509-20318

ROSCOMMON

Brothers of Charity Services –
Roscommon, Lanesboro St,
Roscommon
Tel: 0903-26842

Co Roscommon Association for the
Intellectually Disabled – Ivy House
Castlerea, Co Roscommon
Tel: 0907-20024

SLIGO

North West Parents and Friends
Association
St Joseph’s, Ballytivnan, Sligo
Tel: 071-43358

North Western HSE – Learning
Disability Service, Sligo
Tel: 071-55155

Sisters of La Sagesse Services Cregg
House, Sligo
Tel: 071-77229

TIPPERARY

Arra View Residential and Respite
Services
Emly Road, Tipperary
Tel: 062-51 879

Carrick-on-Suir Camphill Community
Carrick-on-Suir, Co Tipperary
Tel: 051-645080

Co Tipperary Association for Children
and Adults with a Intellectual Disability
Cashel, Co Tipperary
Tel: 062-61866

Grangemockler Camphill Community
Carrick-on-Suir, Co Tipperary
Tel: 051-647120

St Anne's Services – Sean Ross Abbey
Roscrea, Co Tipperary
Tel: 0505-21187

St Cronan's
Grange, Roscrea, Co Tipperary
Tel: 0505-21426

Tipperary Workshop for the
Handicapped Ltd
O'Brien Street, Tipperary Town
Tel: 062-52437

WATERFORD
Brothers of Charity Services
Belmont Park
Waterford
Tel: 051-832211

St John's School,
Dungarvan, Co Waterford
Tel: 058-41860

Sisters of the Bon Sauveur Dungarvan,
Co Waterford
Tel: 058-42808

Waterford Association for the
Intellectually Disabled, Waterford
Tel: 051-875345

WESTMEATH
Sisters of Charity of Jesus and Mary
St Mary's Delvin
Delvin, Co Westmeath
Tel: 044-64108

St Hilda's Services,
Athlone, Co Westmeath
Tel: 0902-75825

St Peter's Centre – Midland HSE
Castlepollard, Co Westmeath
Tel: 044-61115

WEXFORD
Ard Aoibhinn Centre, Wexford
Tel: 053-47868

An Breacadh Nua
Belvedere Road, Wexford
Tel: 053-47868

Camphill Community
Duffcarrig Gorey Co Wexford
Tel: 055-25116

Co Wexford Community Workshop
(New Ross) Ltd
New Ross, Co Wexford
Tel: 051-421956

Co Wexford Community Workshop
Enniscorthy
Enniscorthy Co Wexford
Tel: 054-33069

St Aidan's Day Care Centre Gorey
Co Wexford
Tel: 055-21092

WICKLOW

Co Wicklow Association for the
Intellectually Disabled Ltd
St Catherine's EDC, Newcastle,
Co Wicklow
Tel: 01-2819485

Peacehaven Trust Greystones,
Co Wicklow
Tel: 01-2875977

National S.E.T.C. (Brichualann
Specialised Equestrian Training
College) Bray, Co Wicklow
Tel: 01-2720704

Sunbeam House Services Bray,
Co Wicklow
Tel: 01-2868451

WEXFORD

Wexford Intellectual Disability Services
Dawn House
Belvedere Rd, Wexford
Tel: 053-45351

Wexford Intellectual Disability Services
St. John of God House
Enniscorthy Co Wexford
Tel: 054-33419

Wexford Intellectual Disability Services
Summerhill House
Enniscorthy Co Wexford
Tel: 054-35255

Windmill Therapeutic Training Unit
South Main St, Wexford
Tel: 053-22358

a final note...

THE CITIZENS INFORMATION BOARD

The Citizens Information Board provides information, advice and advocacy over a large range of areas including disability. They can be contacted by accessing their website at: www.citizensinformationboard.ie or ring lo-call 1890-777121.

notes

notes

Members of the The Parents' Future Planning Group

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Kay Conroy

Mark Harrold

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John Davis

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