



**Submission made by
Purple Orange**

**Australian Government's Draft
Baseline Study for the National
Human Rights Action Plan**

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1.0 PURPOSE

This submission is in response to the Australian Government's Draft Baseline study for the National Human Rights Action Plan. Its purpose is to provide further comment regarding the content of the Baseline study in order to inform the Australian Government of an accurate and full picture of the current status of human rights.

2.0 INTRODUCTION

Purple Orange - Julia Farr Association and its predecessor organisations have been involved with the disability community for 130 years. The organisation holds that the following values should inform policy development in this area:

- Personhood – where people living with disability have and exercise control over the decisions in their lives;
- Active Citizenship – where people living with disability are included as active citizens in the life of the wider community;
- Capacity-building – where people living with disability, through access to experiences and support, are growing their presence in personhood and citizenship, and where the wider community is growing its capacity to be welcoming, inclusive and supportive of people living with disability.

Purple Orange is an independent, non-government entity based in South Australia that fosters innovation, shares useful information, and promotes policy and practice that support vulnerable people to access the good things in life. We are not a service provider – we deliver research, evaluation and information services that are anchored upon the stories shared by people living with disability and other people in their lives. As such, we feel we are in a good position to offer comment and analysis without vested interest.

Purple Orange believes that the Australian Government's consultation on the Draft Baseline study is important since it is pivotal to the identification of key priority areas of action to be incorporated in the Human Rights Action Plan. There is a national commitment to "ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities"¹ through the ratification of the UN Convention on the Rights of Persons with Disabilities by Australia in July 2008. While Australia has in place formal mechanisms designed to protect the rights of people living with disability, it is our experience that such mechanisms frequently do not penetrate the everyday life of people living with disability. This consultation provides the opportunity to strengthen Australians capacity and practice to advance and uphold human rights.

¹ United Nations n.d., Convention on the rights of persons with disabilities and optional protocol, accessed 8/2011, p.4, <<http://www.un.org/disabilities/documents/convention/convoptprot-e.pdf>>.

3.0 FEEDBACK ON THE DRAFT BASELINE STUDY

Purple Orange would like to make the following comments:

3.1 INTRODUCTION

3.1.1 What other information (if any) would you include in the introduction?

The introduction contains a summary of Australia's human rights mechanisms and human rights record. The introduction would benefit from a stronger acknowledgement of the marginalised experience of vulnerable groups in Australia. In our experience people living with disability continue to experience impoverished lifestyles characterised by marginalisation and restriction as a result of their human rights not being actively attended to. Whilst the introduction acknowledges that there are challenges and gaps, we believe this understates the extent that people's rights are not being addressed. We believe the introduction needs to provide a more comprehensive, frank perspective of human rights in Australia.

Many people living with impaired decision-making capacity are assumed to be satisfied with whatever services are given and not considered to be capable of having some control in their lives. Their lives are likely to be characterised by poverty, social exclusion, unemployment, and homelessness. These people often experience disadvantage in seeking and receiving health services, and education^{2 3}. They are extremely disadvantaged when faced with the task of ensuring their human rights are upheld in day-to-day situations.

Purple Orange also suggests that it is important to identify precisely who constitutes 'vulnerable groups' in the introduction. We think it would also be important to acknowledge that people have differing capacity in arguing for their human rights to be upheld. This is particularly difficult and unlikely for people living with significant disability⁴. However not all people living with significant disability have difficulty in ensuring their human rights are upheld. People who are vulnerable are diverse and this should be reflected in the introduction.

²Howard and O'Brien (2009) Criminal Injustice of Vulnerable People. Accessed 8/2011: http://www.justice.qld.gov.au/_data/assets/pdf_file/0003/25752/criminal-injustice-for-vulnerable-people.pdf

³ New South Wales Law Reform Commission Report 80 (1996)-People with an Intellectual Disability and Criminal Justice System. Crime and people with an intellectual disability. Accessed 8/2011: <http://www.ipc.nsw.gov.au/lrc.nsf/pages/R80CHP2>

⁴ New South Wales Law Reform Commission (2010) People with cognitive and mental health conditions in the criminal justice system: an overview. Accessed 9/2011: [http://www.lawlink.nsw.gov.au/lawlink/lrc/lrc.nsf/vwFiles/CP05.pdf/\\$file/CP05.pdf](http://www.lawlink.nsw.gov.au/lawlink/lrc/lrc.nsf/vwFiles/CP05.pdf/$file/CP05.pdf)

3.2 CHAPTER ONE: PROTECTION AND PROMOTION OF HUMAN RIGHTS IN AUSTRALIA

3.2.1 What other information (if any) would you include in summarising the key institutional and legal protections and arrangements for promoting human rights in Australia?

Whilst the following initiatives are not directly related to human rights they make a significant contribution to creating a culture where the rights of people living with disability are upheld. These include:

The South Australian Social Inclusion Agenda (Social Inclusion Board of South Australia, 2010)

This is an important document since it aims to strengthen dignity, rights and protection in the lives of people living with disability. It is intended that human rights be upheld as a fundamental principle of South Australian government disability policy and practice. In order to do this stigma, discrimination and exclusion must be eliminated in the community. A part of this is that the community are well-informed about the rights of people living with disability and understand their responsibility to promote participation and inclusion for people living with disability⁵.

Individualised Funding or Self Directed Funding (Productivity Commission, 2011)

Individualised Funding as a mechanism aims to address fundamental issues of self-determination and control, and is, in the main, characterised by the following elements:

- Funding is directly allocated to an individual, not to a specialist disability service;
- Funding is portable – it moves with the individual, and also moves to where the individual prefers to spend that money;
- It facilitates individual control over how monies are spent to meet support needs.
- The amount of funding is determined by direct reference to the individual and their specific needs and aspirations, in either an independent or a family context;
- The individual, either independently, or with assistance from family or other supporters, determine how funds are used;
- It will provide for the support necessary to meet disability related needs and to assist individuals to be/become contributing citizens; and
- Individualised Funding makes a positive contribution to community inclusion options.

The Productivity Commission concluded that a new system of resourcing was feasible in order to achieve much more and better targeted funding to people living with disability and their families. This would serve to promote the right to have choice and control in their lives about the products and services they purchase^{6 7}.

⁵ Social Inclusion Board of South Australia (2010) Activating Citizenship: a Social Inclusion Approach for Disability in South Australia Government of South Australia Access 8/2011: <http://www.socialinclusion.sa.gov.au/files/Activating%20Citizenship%20-%20Social%20Inclusion%20Board%20-%20July%202010.pdf>

⁶ Productivity Commission 2011, Disability Care and Support, Report no. 54, Canberra.

3.3 CHAPTER TWO: HUMAN RIGHTS CONCERNS OF THE GENERAL COMMUNITY

3.3.1 Are there additional concerns that could be included in this section?

On the basis of our experience with people living with disability, Purple Orange draws attention to the following concerns:

Ongoing Denial of Human Rights for People Living with Disability

In our experience alongside people living with disability, Purple Orange is acutely aware of a range of human rights violations such as the right to access public transport, the right to access entertainment and recreational facilities, the right to access justice and the right to be treated with dignity and respect⁸. These violations are occurring in their everyday life. Despite having formal mechanisms in place to protect human rights such as the Disability Discrimination Act 1992, this frequently does not translate to upholding rights in everyday life. Commenting on the adequacy of treaties such as the UN Convention on the Rights of Persons with Disabilities, People with Disability Australia states that “it is now generally accepted that these treaties have done little in practice to protect, promote and fulfil the rights of persons with disability”⁹.

People with Disability Australia goes on to suggest that in part this is because such treaties “both in the formulation and in their implementation have not penetrated to many of the specific forms of human rights violation persons with disability experience”¹⁰.

People living with disability feel let down by human rights processes, legislative protections and complaint mechanisms. People living with disability feel that they are being disempowered and ignored, denied the knowledge and support needed to be heard^{6 11}. For people living with disability their daily life is fraught with obstructions to fundamental rights such as the right to access transport, employment, and housing. Negative perceptions of people living with disability also persist and discriminate against people enjoying the same rights as other members of the community¹². The ongoing frustration of human rights in the daily lives of people living with disability is a serious concern which must not continue.

⁷ Williams R. (2007). Individualised Funding a summary review of its nature and impact, and key elements for success, Julia Farr Association: Adelaide.

⁸ Fidock and Williams (2010), Tell Us Survey Report 3 Accessibility. Julia Farr Association South Australia

⁹ People with Disability Australia Incorporated (2009) submission: National Human Rights Consultation. Accessed 8/2011: <http://www.pwd.org.au/systemic/abuse.html>, p. 11

¹⁰ Ibid, p. 5.

¹¹ 2007 loop conference proceedings accessed May 27, 2011: why is it so hard to speak up and be heard? Accessed 8/2011: http://emilydapc.files.wordpress.com/2008/08/2007_theloop_wrapup1.pdf

¹² Proposed National Disability Insurance Scheme: Human Rights Analysis (2011) Accessed 9/2011: <http://www.vdan.org.au/LinkClick.aspx?fileticket=js0CbPc1K0%3D&tabid=100>

Over-representation of people with impaired decision-making capacity in the legal system

Conveying the human rights status of people living with intellectual disability, the New South Wales Law Reform Commission makes the point that people living with intellectual disability are disadvantaged by:

- An often limited and segregated education;
- Greater likelihood of being unemployed and living on welfare;
- Greater likelihood of living on or just above the poverty line;
- Likely to reside in an unstable accommodation such as boarding houses or hostels;
- Often experiencing stigmatisation and prejudice¹³.

People with impaired decision-making capacity are overrepresented both as victims and alleged offenders in the criminal justice system¹⁴. People who experience cognitive impairment, communication difficulties and/or are non-verbal are particularly disadvantaged when it comes to accessing justice. Typically assumptions are made that these people are unable to be a reliable witness, their testimony is often not seen as credible and therefore not sought. Such people do not fare well in the legal justice system. This also pertains to people experiencing mental health issues¹⁵.

The New South Wales Law Reform Commission identifies a lack of empirical evidence as contributing significantly to the disadvantaged position of people living with disability in the justice system.

Lack of long-term accommodation and support services for people living with disability

Some young people living with disability are forced to live in aged care facilities where they are living among people who are much older. They have no other options available to them because there is a lack of long-term support options in the community for people of their age¹⁶. Not only are people in these situations segregated from their communities but they are also deprived of appropriate social interactions and experiences within the community. The right of people living with disability to choose where they live and who they live with is set down in the UN Convention on the Rights of Persons with Disabilities¹⁷. Essentially this means creating community living opportunities that are similar to those chosen by other

¹³ New South Wales Law Reform Commission People with an Intellectual Disability and the Criminal Justice System: Appearances Before Local Courts (Research Report 4, 1993); and New South Wales Law Reform Commission People with an Intellectual Disability and the Criminal Justice System

¹⁴ Howard and O'Brien (2009) Criminal Injustice of Vulnerable People. Accessed 8/2011:

http://www.justice.qld.gov.au/__data/assets/pdf_file/0003/25752/criminal-injustice-for-vulnerable-people.pdf

¹⁵ New South Wales Law Reform Commission (2010) people with cognitive and mental health conditions in the criminal justice system: an overview accessed 9/2011: [http://www.lawlink.nsw.gov.au/lawlink/lrc/ll_lrc.nsf/vwFiles/CP05.pdf/\\$file/CP05.pdf](http://www.lawlink.nsw.gov.au/lawlink/lrc/ll_lrc.nsf/vwFiles/CP05.pdf/$file/CP05.pdf)

¹⁶ Australian Institute of Health and Welfare, (2009) Younger people with disability in residential aged care: update from the 2009-10 minimum dataset Accessed 8/2011: <http://www.aihw.gov.au/publication-detail/?id=10737419510>

¹⁷ United Nations n.d., Convention on the rights of persons with disabilities and optional protocol, accessed 8/2011, <<http://www.un.org/disabilities/documents/convention/convoptprot-e.pdf>>.

members of the community where people living with disability can make authentic choices about their lifestyle.

The rights of people living with disability as health and community consumers

Currently people living with disability rely heavily upon health and community services for support. This is supported by findings from the 2011 *tellus* survey¹⁸ which highlights that 578 of survey respondents stated that they received personal supports and 362 people stated they received health related supports. Some of this support is of a personal nature. Purple Orange believes it is critical to articulate their rights as health and community consumers. This must be accompanied by effective education strategies both for people living with disability and service providers.

Purple Orange recognises that a power imbalance can exist in the relationship between the service provider and a person living with disability. Therefore, we cannot solely rely upon a complaints mechanism that is dependent upon the person living with disability actively and personally initiating a complaint. There are many reasons why a person may not feel able to initiate a complaint about a service. Purple Orange's 2007 Loop conference explored with people living with disability the question 'Why is it so hard to speak up and be heard?'. The reasons given included lack of confidence, lack of information about where to go and how to give a view, tiredness, fear of retribution, feelings of diminishment, the attitudes and behaviour of people running the system, no collective voice, no focus on solutions and unhelpful processes¹⁹.

The likelihood of a person living with disability actively making a complaint is further diminished when other factors apply, such as:

- *The service agency is also the landlord of the property where the person resides*
When this happens, the stakes are raised significantly for the person who is not happy about services, because if they complain they bring into uncertainty not only their support arrangements but also the roof over their head²⁰;
- *Impoverished family/personal networks*
It is not uncommon for people living with disability, because of circumstances, to be at greater risk of diminished personal networks of family and friends when compared to their non-disabled peer citizens. The relative absence of an active, supportive network of family and friends can contribute to the person's isolation and therefore the degree of their vulnerability²¹. Dependence on relationships with their paid support providers presents a further barrier to speaking up, because doing so may pose a risk to the few

¹⁸ Over 880 people participated in Purple Orange's 2011 *tellus* living with disability survey 2011. The *tellus* survey focuses on painting a picture about the lifestyles of people living with disability by asking respondents to talk about their lives and identify what they think could be different.

¹⁹ 2007 Loop conference proceedings (2007) Why is it so hard to speak up and be heard? Accessed 8/2011: http://emilydapc.files.wordpress.com/2008/08/2007_the_loop_wrapup1.pdf

²⁰ Swift, K 2008, 'Creating home: An exploration of the efforts and commitment to create individual lives, not just bricks and mortar', electronic version, Crucial Times, issue 40, pp. 1-2, <<http://www.cru.org.au/crutimes/CT40/CT40.doc>>.

²¹ Supported Accommodation Task Group 2006, Accommodation and personal support for people with disabilities in South Australia. Consultation paper, Department for Families and Communities, Adelaide, South Australia.

relationships they have. Also the absence of regular visits from, and time with, family and friends, means there is none of the natural 'service monitoring' that takes place through such relationships.

3.3.2 What additional statistical data or research findings could be included to better paint the human rights picture?

Despite a lack of reliable data it is well recognised that people living with disability are overrepresented in the legal and justice system. Howard and O'Brien²² refer to some studies which indicate the overrepresentation of people living with disability in the justice system.

- Adults with intellectual disability are overrepresented in the New South Wales prison population by a factor of four times greater the general population²³.
- More than one third of persons appearing before the New South Wales local courts on criminal charges may have an intellectual disability²⁴.
- More than half of women in Queensland prisons have been diagnosed with a specific mental illness²⁵.
- Based on IQ testing, a 2002 Queensland study found that 9.9% of prisoners scored in the intellectual disability range and 28.6% scored in the borderline intellectual disability range²⁶.

Purple Orange suggests that the human rights picture would be better conveyed if research findings were available which indicated how people living with disability experience aspects of life in comparison to the general population. For example we have standards relating to transport, access, social inclusion, housing etc but are these standards impacting the lives of people living with disability? How do people living with disability compare to the general population on experiences of accessing housing? This information would provide a realistic evidence based picture of how people with increased vulnerability are experiencing human rights issues.

3.3.3 What major existing government initiatives are missing that should be included?

A Human Rights National Action Plan will be considerably strengthened if it has a strong emphasis on assisting people to ensure that their rights are recognised, respected, protected and fulfilled. This will require funding of appropriate advocacy organisations which are capable of ensuring access to justice for these people. A similar initiative

²² Howard and O'Brien (2009) Criminal Injustice of Vulnerable People. Accessed 8/2011: http://www.justice.qld.gov.au/_data/assets/pdf_file/0003/25752/criminal-injustice-for-vulnerable-people.pdf

²³ Hayes and McIlwain, The Prevalence of Intellectual Disability in the New South Wales Prison Population: An Empirical Study (November 1988) 47.

²⁴ New South Wales Law Reform Commission People with an Intellectual Disability and the Criminal Justice System: Appearances Before Local Courts (Research Report 4, 1993); and New South Wales Law Reform Commission People with an Intellectual Disability and the Criminal Justice System:

²⁵ Anti-Discrimination Commission Queensland, Women in Prison, March 2006, 5.

²⁶ Queensland Department of Corrective Services, Intellectual Disability Survey (2002). Two Rural Courts (Research Report 5, 1996).

accompanied the Disability Discrimination Act where disability discrimination legal services were funded in each Australian state and territory to assist people to exercise their human rights²⁷.

Such advocacy agencies provide an independent, free and confidential service. This would be achieved through the delivery of information, referral, support, advice and/or representation of both individuals and groups.

3.4 CHAPTER THREE: THE HUMAN RIGHTS EXPERIENCE OF SPECIFIC GROUPS IN AUSTRALIA

3.4.1 Are there additional specific groups that could be included in this section?

Purple Orange recommends that the section on people living with disability be strengthened.

Purple Orange suggests the section on people living with disability (section 3.7) should draw attention to the fact that many people living with disability experience social exclusion as part of everyday life. In our experience this partly relates to a lack of familiarity and knowledge about what the term 'social exclusion' means in practical terms both for people living with disability and the community. Social exclusion may manifest as obstructions to accessing a buildings and public spaces, transportation and other facilities that assist the flow of community life and relationships. Negative attitudes toward disability reflect a 'medical model' of disability which results in segregation, services and dependency²⁸. It is very important that we shift from this paradigm to a social model of disability which emphasises social inclusion and the creation of a supportive environment so that people living with disability have choice, control and optimal independence.

The reality is that the stigma attached to disability and high levels of discrimination act as barriers to social inclusion. Any effective mechanisms to promote social inclusion and make life different for people living with disability in Australia will need to be anchored upon a human rights framework which actively supports their rights.

3.4.2 What additional statistical data or research findings could be included to better paint the human rights picture for a specific group?

Tellus Survey report 3 - Accessibility

The *tellus* survey report on accessibility focuses on the importance of people living with disability having good access to places and services within the community. There is a particular focus on accessing public transport, public premises and primary healthcare services. The key findings of the 2010 *tellus* survey, based on nearly 800 survey responses,

²⁷ People with Disability Australia Incorporated (2009) submission: National Human Rights Consultation Accessed 8/2011: <http://www.pwd.org.au/systemic/abuse.html>

²⁸ Brett and Kavanagh (2008) Reframing Disability in the Higher Education. Accessed 8/2011: www.adcet.edu.au/StoredFile.aspx?id=2374&fn=M+Brett+-+paper

show that over half the respondents living with disability found it difficult to use public transport from where they lived, over a quarter experience problems accessing places within the community, and an average of 15% did not find it easy to access health support from their general practitioner. The report discusses these findings in the context of the UN Convention on the Rights of People with Disabilities together with national legislation and regulations. It also notes the benefits of raising awareness in the community about the importance of people living with disability having ready access in their community to those things that most other citizens take granted²⁹.

Views from the Loop Conference 2007 and 2008

The Loop Conference was established in response to an awareness that people living with disability found it hard to get to a city due to issues of cost, mobility, support needs or a lack of public transport. The Loop takes the conference out to a number of different venues around South Australia. The intended emphasis of the Loop is to 'talk with' people not to 'talk at'. The aim is a conversation between all participants including the presenters. Participants provide information about their perspective and experiences on different topics which are then written up and reported on in the relevant documents and other media opportunities³⁰.

Overrepresentation as victims of crime

There is strong evidence to indicate that people living with disability are overrepresented as victims of crime, violence, fraud and sexual assault. They are also more likely to experience multiple episodes of all forms of abuse and neglect^{31 32}. This is important background information in the context of human rights for people living with disability.

The legal system's treatment of people living with disability

People living with disability experience inequitable and discriminatory treatment when participating in the legal system both as victims of crime and as the accused or offender³³. This information needs to inform key priority areas for action.

²⁹ Fidock and Williams (2010), Tell Us Survey Report 3 Accessibility. Julia Farr Association South Australia

³⁰ Williams, (2009) Why Is It so Hard to Speak up and Be Heard? Views from the loop conference 2007

³¹ French, Dardel and Price-Kelly, (2010). Right's denied: towards a national policy agenda about the abuse, neglect and exploitation of persons with cognitive disability in Australia. Accessed May 27, 2011: http://www.hreoc.gov.au/disability_rights/hr_disab/vhb/index.html

³² Keilty, J. and Connelly, G. (2010). Making a Statement: An exploratory study of barriers facing women with an intellectual disability when making a statement about sexual assault to police. Intellectual Disability Rights Service. Surry Hills, NSW. 25 pgs.

³³ French, P. (2007). *Disabled Justice: The barriers to justice for persons with a disability in Queensland*. Queensland Advocacy Incorporated. Brisbane. 152 pgs.

3.4.3 Are there any additional human rights issues that could be added which affect the specific groups identified in this section?

As already mentioned people living with disability experience ongoing human rights violations when they attempt to navigate a pathway toward an ordinary, valued life.

Current research being conducted at Purple Orange collecting the stories of 100 people living with disability who have achieved a level of independence and participation in their community highlights the human rights obstructions they have had to negotiate to achieve their goals. Sometimes this relates to the inability of parents to access education options for a young person living with disability, inability to access employment, recreational opportunities, community living options and community support. The stories highlight examples where due to lack of support people have been unable to attend celebrations such as New Year's Eve and a family member's birthday.

3.4.4 What further actions or desired outcomes would you include to protect or promote human rights?

Sterilisation procedures for women living with intellectual disability

Purple Orange agrees with the baseline study in describing the grave form of human rights abuse that non-therapeutic sterilisation of women with an intellectual disability presents, particularly when it is done without their consent. Typically in the past young women living with intellectual disability have been subject to sterilisation procedures based on parental fear and anxiety. In some situations this has occurred without the consent of the young woman living with intellectual disability³⁴. The long-term psychological and emotional impact of non-therapeutic sterilisation for young women is not known.

The Royal Australian and New Zealand College of Obstetricians and Gynaecologists³⁵ recommend that when addressing issues of fertility control for women living with intellectual disability, the least restrictive option and approaches which are similar to those one would consider for women of the same age who do not have an intellectual disability, are the most appropriate.

They also stipulate that reversible methods such as long acting reversible contraceptive implants (e.g. Implanon or Mirena) should be considered in preference to irreversible surgical options. The administration of treatment to a woman living with intellectual disability must be in accordance with the current law and guardianship provisions of the relevant jurisdictions³⁵.

³⁴ Spicer (1999) Sterilisation of Women and Girls with Disability-A Literature Review. Accessed 8/2011: www.wvda.org.au/steril.htm

³⁵ The Royal Australian and New Zealand College of Obstetricians and Gynaecologists (2010) sterilisation procedures for women with an intellectual disability. Accessed 8/2011: <http://www.ranzcog.edu.au/publications/statements/C-gyn10.pdf>

Purple Orange suggests that it is unacceptable that non-therapeutic sterilisation can occur in the absence of consent by the woman on whom it is being performed. This area of human rights requires further protection.

3.4.4.1 *What specific measures would you suggest to address these issues?*

Purple Orange suggests that as a society we would not accept the sterilisation of nondisabled girls and women without their consent. Purple Orange advocates the development of current law and guardianship provisions to be consistent with protecting the rights of women living with intellectual disability. This should be accompanied by creative approaches to the optimisation of consent by women living with intellectual disability. The voices of women living with disability who have experienced nontherapeutic sterilisation are absent from debate about this issue and should be sought.

3.5 DO YOU HAVE ANY OTHER COMMENTS OR SUGGESTIONS FOR IMPROVING THIS BASELINE STUDY?

Purple Orange suggests that it is important to strengthen a realistic picture of the status of human rights for people living with disability. In our view the current Draft Baseline study does not provide a true picture of the ongoing denial of human rights that people living with disability experience.

4.0 CONCLUSION

Purple Orange appreciates the opportunity to provide comment on the Draft Baseline study. The importance of human rights for people living with disability is paramount and a central focus of our organisation. We consider that an extensive implementation plan is needed to ensure that human rights penetrate the daily lives of people living with disability. We welcome the opportunity to identify components of an effective implementation strategy.

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